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TAILORING AND STANDARDIZING THE ASSESSMENT OF ABILITY AND DISABILITY IN ADHD AND AUTISM: THE DEVELOPMENT OF WHO ICF CORE SETS

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Tailoring and Standardizing the Assessment of Ability and Disability in ADHD and Autism: The Development of WHO ICF Core Sets

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To my parents, Ehsan and Rooha, and my siblings, Saman, Sepehr and Tanja.

ABSTRACT

The concept of health has evolved over time and is today considered a multidimensional construct that involves not only absence of impairments or pathologies, but also quality of life and individual functioning. This conceptualization is especially important to individuals with neurodevelopmental disorders (NDD), as these are characterized by early-onset symptoms that tend to persist into adulthood, interfering with individual well-being, daily life activities and engagement in society. The lack of well-established tools for functioning assessment in NDD marks a significant gap, as there is a substantial interindividual variation in severity of functioning and profile of individual limitations and resources. Hence, diagnosis alone is not sufficient enough to understand individual health outcome in NDD. In 2001, the World Health Organization (WHO) launched the International Classification of Functioning, Disability and Health (ICF), a classification system based on a biopsychosocial framework which seeks to describe and understand health-related functioning, allowing all aspects of an individual's life to be taken into account. However, the ICF in its current form comprises over 1600 categories of health-related functioning aspects, which makes the implementation of the nomenclature rather infeasible and undesirable in clinical and daily practice. To facilitate the implementation, shorter versions of ICF (i.e. Core Sets) have been developed to describe specific condition or condition groups. This thesis is part of the overarching aim to develop ICF Core Sets (ICF-CS) for two common NDD, i.e. Attention-Deficit/Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD), to standardize individual assessment of functioning and disability in ADHD and ASD.

The development of ICF-CS followed a rigorous and scientific procedure, as established by the World Health Organization (WHO) and the ICF Research Branch, which comprised a series of preparatory studies aiming to investigate relevant aspects of functioning and disability in ADHD and ASD using multiple stakeholder perspective and cross-cultural data sample. In this thesis, two of four preparatory studies are included, of which one explored the client and social environment perspective, whereas the other examined the clinical perspective on functional health in ADHD and ASD. Since the preparatory studies were conducted separately for ADHD and ASD, these resulted in four scientific papers which are included in the thesis.

Study I-II consisted of a mixed qualitative-quantitative study design, involving clients with ADHD/ASD (children, adolescents, adults), caregivers and professionals participating in focus group discussions or individual interviews across five countries and WHO-regions (i.e. Africa, Eastern Mediterranean, Europe, South East Asia, The Americas). The participants were divided into different groups based on age group, stakeholder perspective and country. All discussions and interviews were audio-recorded and transcribed verbatim with meaningful concepts extracted from the transcriptions and linked to ICF categories following a meaning condensation procedure. In study III-IV, a cross-sectional study design was employed, with clinical researchers rating the functioning level of individuals with ADHD and ASD using a checklist with ICF categories. Various types of information sources (e.g.

interviews with clients/caregivers, clinical observation, test results, rating scales, medical records) were used to complete the rating.

Study I (ADHD) included 76 participants, which generated 82 ICF categories (32 activities and participation; 25 environmental factors; 23 body functions; 2 body structures), 243 personal factors (e.g. personality traits, personal attitudes, behavior patterns) and 4 recurring strengths (e.g. creativity, hyper-focus). The categories in the activities and participation component and environmental factors represented all nine (i.e. learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; community social and civic life) and five chapters (i.e. products and technology; natural environment; support and relationships; attitudes; services, systems and policies), respectively. Body functions comprised mainly of mental functions, but other areas of the body were also identified, including cardiovascular, sensory, digestive and motor functions. Study II (ASD) included 90 participants, which resulted in 110 ICF categories (45 activities and participation; 33 body functions; 29 environmental factors; 3 body structures), 492 personal factors (e.g. life-habits, personal attitudes, behavior patterns) and 6 recurring strengths (e.g. memory, attention, temperament and personality). The activities and participation component and environmental factors included categories from all nine and five chapters, respectively. Body functions consisted mostly of mental and sensory functions, even though other areas of the body also had some coverage (e.g. digestion, exercise tolerance, motor functions).

In study III (ADHD), 112 clinical cases were contributed from eight countries and four WHO-regions (i.e. Eastern Mediterranean Europe, South East Asia, Western Pacific). In total, 113 ICF categories (50 activities and participation; 33 environmental factors; 30 body functions), 212 personal factors (e.g. life situation/sociocultural factors, personal attitudes, personality traits) and 22 ADHD-related strengths (e.g. social skills, attention, memory) were identified. Similar to study I, all nine and five chapters were covered in the activities and participation component and environmental factors, respectively. Body functions consisted mainly of mental functions, albeit other areas of body functions were identified in this study which were not covered in study I, such as reproductive and speech functions. No body structures were represented in this study, contrary to study I, which covered 2 body structures. Study IV (ASD) comprised 122 cases from ten countries and four WHO-regions (i.e. Eastern Mediterranean, Europe, The Americas, Western Pacific), generating 139 ICF categories (64 activities and participation; 40 body functions; 35 environmental factors), 148 personal factors (e.g. personal attitudes, personality traits, mental factors) and 3 ASD-related strengths (e.g. memory, attention). Categories were from all chapters in the activities and participation and environmental factors component. Most body functions were mental functions, but still this study identified broader aspects of body functions compared to study II, including reproductive and voice and speech functions. This study did not cover any body structures, unlike study II, which included 3 body structures.

The large variety of activities and participation categories identified in the different preparatory studies attest to the complexity of ADHD and ASD and the necessity of having a functioning-oriented perspective on well-being and health. Interestingly, certain areas of activities and participation, which are not extensively covered in research or clinical practice, were highlighted as important areas to explore, such as participation in community and civic life, domestic life, self-care and mobility (i.e. using transportation). The chapter coverage of environmental factors was similar to activities and participation, regardless of study and diagnosis, which shows that factors in the environment are vital to assess in order to understand and optimize individual functioning in daily practice. Given that ADHD and ASD are complex diagnoses with heterogeneous impact on well-being and functioning, it is not surprising that different aspects of the environment are highlighted as important determinants of individual health. Body functions comprised mainly of mental functions, but findings suggest other areas of the body to be affected in ADHD and ASD, hence emphasizing an interdisciplinary service and assessment approach. Although not coded in the ICF, the preparatory studies showed that personal factors could add additional information on functioning which may be essential to intervention planning or goal-setting.

In the future, tools will be derived from the ICF-CS for ADHD and ASD and implemented in different settings (e.g. clinics, schools, social services) that play major part in the lives of individuals with ADHD and ASD. The categories in the ICF-CS need to be operationalized into useful items which users (e.g. clinicians, clients, caregivers) can rate with ease and clarity. Users should also be free to add missing ICF categories or add information on strengths, personal factors or other contextual factors which may be pivotal to their everyday life functioning. Qualitative and quantitative outcome measures need to be used to evaluate usefulness of the items as well as administration. Future studies should investigate psychometric properties of ICF-CS based assessment tools and explore how the different ICF components and categories may relate to each other.

SCIENTIFIC PAPERS INCLUDED IN THE THESIS

I. **Mahdi, S**., Viljoen, M., Massuti, R., Selb, M., Almodayfer, O., Karande, S., de Vries, P., Rohde, L., Bölte, S. (2017). An international qualitative study of ability and disability in ADHD using the WHO-ICF framework. *European Child & Adolescent Psychiatry*, 26, 1219-1231.

II. **Mahdi, S**., Viljoen, M., Yee, T., Selb, M., Singhal, N., Almodayfer, O., Granlund, M., de Vries, P., Zwaigenbaum, L., Bölte, S. (2018). An international qualitative study of functioning in autism spectrum disorder using the World Health Organization International Classification of Functioning, Disability and Health Framework. *Autism Research*, 11, 463-475.

III. **Mahdi, S**., Ronzano, N., Knüppel, A., Dias, J.C., Albdah, A., Chien-Ho, L., Almodayfer, O., Bluschke, A., Karande, S., Huang, H-L., Christiansen, H., Granlund, M., de Vries, P., Coghill, D., Tannock, R., Rohde, L., Bölte, S. (2018). An international clinical study of ability and disability in ADHD using the WHO-ICF framework. *European Child & Adolescent Psychiatry*, 27, 1305-1319.

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SCIENTIFIC PAPERS NOT INCLUDED IN THE THESIS

I. de Schipper, E., **Mahdi, S**., Coghill, D., de Vries, P.J., Shur-Fen Gau, S., Granlund, M., Holtmann, M., Karande, S., Levy, F., Almodayfer, O., Rohde, L., Tannock, R., Bölte, S. (2015). Towards an ICF core set for ADHD: a worldwide expert survey on ability and disability. *European Child & Adolescent Psychiatry*, 24, 1509-1521.

II. de Schipper, E., **Mahdi, S**., de Vries, P., Granlund, M., Holtmann, M., Karande, S., Almodayfer, O., Shulman, C., Tonge, B., Wong, V.C.N., Zwaigenbaum, L., Bölte, S. (2016). Functioning and Disability in Autism Spectrum Disorder: A Worldwide Survey of Experts. *Autism Research*, 9, 959-969.

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CONTENTS

LIST OF ABBREVIATIONS

ABAS-2	Adaptive Behavior Assessment System -second edition
ADHD	Attention-Deficit/Hyperactivity Disorder
ADI-R	Autism Diagnostic Interview -Revised
ADOS-2	Autism Diagnostic Observation Schedule -second edition
ASD	Autism Spectrum Disorder
BRIEF	Behavior Rating Inventory of Executive Function
Brief ICF-CS	Brief ICF Core Set
CBT	Cognitive Behavioral Therapy
C-GAS	Children's Global Assessment Scale
Comprehensive ICF-CS	Comprehensive ICF Core Set
CPT-3	The Conners Continuous Performance Test -third edition
CRF	Case record form
CRPD	Convention on the Rights of Persons with Disabilities
CSI-SY	The Communication Supports Inventory -Children & Youth
D-KEFS	Delis-Kaplan Executive Function System
DSM-5	Diagnostic and Statistical Manual of Mental Disorders -fifth edition
GAF	Global Assessment of Functioning
GI-issues	Gastrointestinal issues
ICD	International Statistical Classification of Diseases and Related Health Problems
ICF	International Classification of Functioning, Disability and Health
ICF-CS	ICF Core Sets
ICF-CY	International Classification of Functioning, Disability and Health -Children & Youth Version
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ILCD	International List of Causes of Death
NDD	Neurodevelopmental disorders

NRS	Numeric Rating Scale
PDD-NOS	Pervasive Developmental Disorder -Not Otherwise Specified
QoL	Quality of Life
SC	Steering Committee
SNRI	Serotonin-norepinephrine reuptake inhibitors
SRS	Social Responsiveness Scale
UPIAS	Union of the Physically Impaired Against Segregation
VABS	Vineland Adaptive Behavior Scale
WHO	World Health Organization
WHODAS 2.0	World Health Organization Disability Assessment Schedule 2
WISC-V	Wechsler Intelligence Scale for Children -fifth edition

ABOUT THIS THESIS

This thesis is part of an overarching effort to develop International Classification of Functioning, Disability and Health (ICF) Core Sets for Attention-Deficit/Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) to tailor and standardize individual assessment of functioning and disability. As part of this development procedure, two cross-cultural studies were conducted to investigate different stakeholders' perspectives on relevant aspects of functioning and disability in ADHD and ASD as operationalized by the ICF. Given that the studies were conducted separately for ADHD and ASD, this thesis consists of four scientific papers. Study I-II aimed to explore the opinions of diagnosed clients with ADHD and ASD, caregivers and professionals on important aspects of functioning and disability in ADHD and ASD. Study III-IV aimed to investigate the clinical perspective on ADHD and ASD by applying a multicenter, cross-sectional design that involved clinical researchers rating the functioning level of individuals with ADHD and ASD. The structure of the thesis is as follows:

Chapter 1 provides an introduction to the thesis with information about different conceptualizations and models of health. This part is followed by a section about neurodevelopmental disorders (NDD), specifically ADHD and ASD, and their impact on functioning and quality of life. Limitations in clinical guidelines and assessment of ADHD and ASD are discussed, with emphasis on the lack of a unifying framework or classification system that enables assessment of individual health beyond the boundaries of psychopathology or impairments. The introduction part is then concluded by a section about the ICF, its background, rationale, framework and application areas. Challenges with applying the ICF are discussed, including the need for shorter versions of ICF (i.e. ICF Core Sets) that allows users to capture relevant aspects of functional health for specific diagnoses, in this case ADHD and ASD.

Chapter 2 describes the aims and rationale of the thesis.

Chapter 3 describes the method section, namely ethical considerations, study design, procedure, participants, material and data analysis.

Chapter 4 describes the results of the different studies, with information about second-level ICF categories that were identified across various components and chapters. Recurring personal factors are also summarized here along with results on ADHD and ASD-related strengths.

Chapter 5 discusses the findings from the different studies, relating them to previous research as well as mentioning the implications they may have for daily practice. Study limitations and considerations are also discussed here.

Chapter 6 provides the conclusions of the thesis as well as future directions with the project, focusing on deriving user-friendly assessment tools from the ICF Core Sets for ADHD and ASD and implementing these in daily practice.

1 INTRODUCTION

1.1 MODELS AND CONCEPTUALIZATIONS OF HEALTH

The concept of health has evolved over time, much due to improved living standards and advances in medical treatment that have enabled individuals with illnesses to not only survive for a longer period of time, but also actively participate in society (Jetté et al. 2010). This development makes the assessment of non-fatal outcomes, such as individual functioning and quality of life, vital in daily practice, particularly in mental health, as some conditions may be stable over time and interfere with daily life activities and involvement in society. Hence, the definition of health as "merely absence of disease or illness" is insufficient, as evidenced by the World Health Organization's (WHO) decision in 1948 to adopt a holistic definition which viewed health in a broader manner, encompassing other vital dimensions, including physical, mental and social well-being as important determinants of health (WHO, 2014). In 1984, the WHO further elaborated on this issue when individual aspirations and satisfaction of needs, as well as ability to cope with the environment were added as essential components in the conceptualization of health (WHO, 1984). Based on the actions undertaken by the WHO, one can conclude that assessments of health must take into account all aspects of life and not merely focus on morbidities or illnesses. Throughout history, various models have been introduced to explain health and disability, with enormous implications for healthcare providers and society as a whole.

1.1.1 Medical model

The medical model, which has traditionally been used to explain and treat disorders in psychiatry, posits that symptom complaints have biological causes that can be remedied using medical treatment to restore deviations in body processes and structures (Deacon, 2013). The model emerged as a popular framework in the middle of 20th century, in part due to pharmacological interventions successfully reducing symptoms of various psychiatric disorders. The success further cemented the role of the medical model in explaining disability and health and etiological theories of chemical imbalances in mental disorders soon followed, challenging the old paradigm which viewed mental disorders as outcome of poor parenting. The biological perspective was intended to decrease stigmatization by viewing patients as innocent victims of brain aberrations that produced specific symptoms. The patient was expected to be passive recipient of treatment, meaning that medical doctors had an active role in deciding how treatment should be administered. The medical model has been highly influential in assessment, service provision and resource allocation for people with psychiatric disorders. Current diagnostic procedure includes for instance using different assessment tools to identify core behavioral domains of disorders and many service providers follow a disorder-specific approach with separate services for people with physical disabilities and mental health problems (BUP SLL, 2015; Wade & Halligan, 2004). Moreover, funding is still in some societies determined by guidelines that involve meeting criteria for specific diagnoses (Wade & Halligan, 2017).

Although the medical model has vastly improved our knowledge and understanding of neural mechanisms underlying specific psychiatric disorders, it has been criticized on numerous accounts. Firstly, the medical model emphasizes the biological aspect of health (i.e. psychopathology), thus leading to interventions mainly focused on reducing symptoms through usage of medication (Deacon, 2013), which can be particularly problematic in certain conditions where medication is not listed as evidence-based treatment option (DeFilippis & Wagner-Dineen, 2016; Hsia et al. 2014; LeClerc & Easley, 2015). Another criticism relates to the medical model focusing too much on modifying individual traits rather than changing the environment to better fit individual needs of people with disabilities (Deacon, 2013). It is a well-known fact that facilitators in the environment (e.g. parental commitment, accepting attitudes) can positively influence individual outcome, whereas barriers (e.g. limited accessibility to evidence-based programs, negative attitudes) can reduce functioning status (Kirby, Baranek & Fox, 2016; Lebowitz, 2016). Finally, the medical model has been criticized for not sufficiently addressing individual experiences and feelings of health (Engel, 1977), which makes the assessment of other health-related dimensions, such as functioning and quality of life, difficult to measure. Limited understanding about individual functioning in everyday life is particularly problematic in mental health conditions, as there is a substantial individual variation in how strengths and difficulties are presented in real life (Masi, DeMayo, Glozier & Guastella, 2017), hence making it almost impossible to design interventions that are in line with individual needs. The shortcomings of the medical model have therefore prompted researchers to propose other types of models to explain disability and health.

1.1.2 Social model

The social model emerged in the 1970s in the United Kingdom when the Union of the Physically Impaired Against Segregation (UPIAS) published a document arguing for a shift in how disability and health is defined (UPIAS, 1976). Unlike the medical model, this model breaks the link between impairment and disability, emphasizing the social aspect of health, meaning that disability is not caused by impairments in the body but rather barriers in society that limit opportunities for individuals to participate in mainstream social, educational and occupational activities (Oliver & Barnes, 2010). Although the social model recognizes the reality of impairments, it views disability as outcome of hindering environmental factors, ranging from stigmatizing cultural and social attitudes to lack of accessibility in programs, services and policies. Consequently, solutions should not target the individual but rather the society, and improvement should be considered as change in political and social action instead of change in physical body (Bingham, Clarke, Michielsens & Van De Meer, 2013). The social model of disability has inspired number of laws and regulations that endorse implementation of social change to enhance participation. These include the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) (2006) and the Salamanca Statement and Framework for Action on Special needs (1994), which emphasize inclusive-oriented approaches as the most effective means to achieve education and employment for all people. On national level, the Swedish Parliament decided in 1993 on the Swedish Act

concerning Support and Service for Persons with Certain Functional Impairment to ensure that individuals with extensive and permanent functional impairments are guaranteed special support related to domestic life, occupation and self-care. A couple of years later, the Swedish Mobility Service Act (1997) came into force, allowing individuals with impairments to use alternative transportation means (i.e. taxi) to carry out daily errands. Similar developments have taken place in other countries as well, including Australia (Disability Discrimination Act 1992), Hong Kong (Disability Discrimination Ordinance of 1995), South Africa (Promotion of Equality and Prevention of Unfair Discrimination Act, 2000), the United Kingdom (Disability Discrimination Act 1995; now repealed and replaced by Equality Act 2010) and the United States (Americans with Disabilities Act of 1990), among others. Besides international policies and regulations, the social model has also played a role in creation of disability rights movements who adhere to the notion of removing environmental barriers to meet individual needs of people with disabilities (Oliver, 2013). One of the most influential movements is the autism rights movement which advocates for a neurodiversity perspective, encouraging individuals, caregivers and other members in society to accept autism as a variation in functioning rather than a mental disorder (Robertson & Ne'eman, 2008). Additional goals include working for greater acceptance of autistic behaviors and creation of social networks that would allow individuals to socialize on their own terms.

While a growing number of countries and organizations have laid the foundation for meaningful change, there is still a long way to go with regards to how inclusive-oriented programs and systems are interpreted and implemented (Pellicano, Bölte & Stahmer, 2018). A survey conducted in Sweden, which included almost 4800 school-based personnel, revealed that only 6 % of the participants felt that they were prepared to educate pupils with neurodevelopmental disorders (Bartonek, Borg, Berggren & Bölte, 2018). Remarkably, 14 % indicated they had formal education in teaching pupils diagnosed with neurodevelopmental disorders. The lack of staff understanding and recognition of needs in diagnosed pupils has previously been documented in other studies with serious consequences, including social isolation, exclusion from school-related activities and expulsion (Atkinson, 2013; Brede, Remington, Kenny, Warren & Pellicano, 2017; Roberts & Simpson, 2016). In another study, results showed that many interventions for individuals with neurodevelopmental disorders focused on impairment and modification of individual traits (e.g. teaching people problem-solving skills) rather than being the intervention itself (e.g. using headphones to protect from noisy environment) (Scott et al. 2018). The findings here attest to the discrepancy that exists between what is enforced by national laws and how it is implemented in real life. The reasons for this discrepancy are complex, but some suggest that the term inclusion is vague and that there are no clear guidelines for how inclusion should be implemented in daily practice (Pellicano et al. 2018). Others criticize the social model for separating impairments from disability (Haegele & Hodge, 2016; Shakespeare, 2010), stating that it would be nearly impossible to understand how changes in the environment should be implemented without accounting for how impairments may influence individual health. Additional criticisms include the social model's implicit emphasis on achieving a "barrier-free utopia" with all

sorts of barriers removed, which is not plausible in real life, given that some environmental elements may be difficult or even impossible to adapt (e.g. adapting a mountain to fit the need of someone who is in a wheelchair) (Shakespeare, 2010). Finally, the social model has been criticized for not taking into account individual differences that may exist between people with disabilities (Haegele & Hodge, 2016; Shakespeare, 2010). For example, people with different impairments may require solutions that differ from one another. A blind person may for instance prefer steps and defined curbs, whereas someone in a wheelchair may rather use ramps and smooth surfaces.

1.1.3 Biopsychosocial model

In 1977, the American psychiatrist George L. Engel proposed a biopsychosocial model to understand health outcome. He criticized the medical model's overreliance on explaining health from a biological standpoint and highlighted the need for complementary information that accounted for individual experiences of health as well as social influences (Engel, 1977). However, unlike the social model, Engel acknowledged the importance of biological impairments and defined the development of health as a series of complex interaction involving biological, psychological and social factors along a continuum of natural systems (Engel, 1980). The natural system is organized into different levels of complexity, with larger units that are superordinate to less complex and smaller units. Each unit has a distinctive property and characteristic that justifies its position in the hierarchy. For example, cells are smaller units to tissues, which in turn is an inferior system to organs. Lowest in the hierarchy is systems related to biological factors, encompassing smaller (i.e. molecules, organelles, cells) and larger biological units (i.e. tissues, organs, nervous system). The individual, which is made up of human experiences and behaviors, is considered to be in the highest level of organismic hierarchy, while at the same time constituting the smallest unit in the social hierarchy, meaning that each system can be both a whole or part of a larger system. The social hierarchy consists of the environment, which is organized into different levels of systems based on complexity, starting with two people (i.e. family member, friend, professional caregiver), family (i.e. nuclear, extended) and community (i.e. healthcare, work, residential setting, neighborhood) to higher levels of complexity such as culture/subculture (i.e. norms, values), society/nation (i.e. economic, political forces) and biosphere. Even though lower levels of systems are necessary for higher ones to exist, they are not sufficient enough to explain or understand their nature without accounting for superior systems. A patient can for instance be described in terms of certain characteristics (e.g. sex, age, marital status, occupation, residence etc.) that identify other systems of which the patient is part of (e.g. family, community, culture). In other words, nothing exists in isolation and all systems interact with one another. Therefore, it is vital that healthcare providers address all aspects of an individual's life in order to understand the totality of individual health experiences.

The biopsychosocial model has received wide attention around the world, as evidenced by the WHO's adoption of the model as framework to appraise and document health-related functioning (Üstün, Chatterji, Bickenbach, Kostanjsek & Schneider, 2003). In clinical

practice, the model has mainly gained prominence in services related to chronic pain, rehabilitation and habilitation (Wade & Halligan, 2017). The latter is usually made up of interdisciplinary teams that aim to provide interventions that target participation in various life areas, emphasizing close collaboration with the client and social environment (Adolfsson, Granlund, Björck-Åkesson, Ibragimova & Pless, 2010). Notwithstanding the growing trend of the biopsychosocial model, the implementation of the framework in everyday practice is still limited. In healthcare administration systems, diagnoses and core symptoms are routinely documented (Wade & Halligan, 2017), even though these are too futile to be useful for intervention planning and calculation of health-related costs. It's important, however, to stress that a transition from an old paradigm to a new one takes time and effort. Collaboration across professional boundaries requires trust and sharing, as well as consensus on how to proceed and understand a certain situation from a biopsychosocial perspective. Evidently, this could be facilitated by a framework or classification system that uses a common language that would allow various professionals to communicate information with ease and clarity. The absence of such framework could therefore be a barrier. Other critics state that the biopsychosocial model is too broad (Ghaemi, 2009) and that the exact mechanisms involved in the interaction between the various factors included in the model, especially the human-environment interaction, are not clearly defined (Batorowicz, King, Mishra & Missiuna, 2015).

1.1.3.1 Bronfenbrenner's ecological systems theory

The ecological systems theory was formulated in 1979 by psychologist Urie Bronfenbrenner to explain how different aspects of the environment may influence the development of an individual. Bronfenbrenner argued that influences of the environment can be divided into different levels of systems (Bronfenbrenner, 1994), from proximal to distal, namely microsystem, mesosystem, exosystem, macrosystem and chronosystem. Microsystem is the most proximal setting and refers to the immediate environment of the individual, which includes people that the individual interacts with on daily basis (e.g. peers, parents, teachers), physical settings (e.g. school, work, home) and objects/products (e.g. food, toys, computer). How these factors interact with the individual will impact growth and development; the more resources, nurture and support are provided, the better the prerequisites for favorable outcome. Next level is mesosystem, which touches upon the interaction between the various factors within the microsystem (e.g. teacher-parent interaction, relationship between the parents). Although the individual is not directly involved here, conflicts in the various support groups may nevertheless jeopardize the emotional growth of the individual. The exosystem represents resources or infrastructure that are included in the wider environment of the individual. Examples include services and policies offered by various authorities (e.g. social services, healthcare, employment agency, etc.). The availability of these factors could have a profound impact on the individual, either positively (e.g. availability of supported employment for individuals with disabilities) or negatively (e.g. lack of services to meet needs of individuals with disabilities). The macrosystem is the most distal level and describes the norms, values and culture in which the individual lives. Chronosystem adds the

dimension of time, reflecting the influences of proximal (e.g. change in family structure or residence) and societal changes (e.g. economic cycles, natural disasters, wars). Bronfenbrenner remarked that the different systems interact with one another. For example, certain stigmas in society (macrosystem) may influence availability of specific services and policies (exosystem), which in turn could impact the lives of family members and the individual in question.

Later in life, Bronfenbrenner made some revisions in the ecological systems theory to emphasize bidirectional influences between individuals and their environment (Bronfenbrenner, 2005; Bronfenbrenner & Evans, 2000; Bronfenbrenner & Morris, 1998). Specifically, human development is shaped through the processes of reciprocal interactions that take place between an active individual and his or her immediate environment. Such interaction is called proximal process, which must occur frequently over an extended period of time in order to facilitate positive outcome in development. Positive outcome is defined as acquisition and further advancement of skill sets, knowledge and ability to manage behaviors, whereas negative development is characterized by recurring difficulties to control and integrate behaviors across different life domains (Bronfenbrenner & Evans, 2000). Proximal processes are influenced by individual characteristics and qualities of the environmental setting, which includes both immediate and remote contexts (as described in the ecological systems theory), as well as time (Bronfenbrenner, 2005). Bronfenbrenner identified three individual characteristics to be crucial in influencing proximal processes across the lifespan, namely demand (i.e. age, gender, physical appearance), resource (i.e. past experiences, intelligence, skill sets) and force (i.e. motivation, persistence, temperament). Thus, individuals may have equal access to environmental support, but still differ in developmental course, as they may vary in demand, resource and force characteristics. Time is defined according to three levels, namely microtime, mesotime and macrotime. Microtime describes continuity and discontinuity in ongoing episodes of proximal process (i.e. what is happening during the proximal process), whereas mesotime touches upon the extent to which these reciprocal interactions occur within days, weeks and years (i.e. duration, frequency). Macrotime represents changes in expectations and events in the larger society and how these may impact proximal processes. Newer models, such as the integrated model of social environment and social context, has further elaborated on the theoretical foundations laid by Bronfenbrenner, reinforcing the importance of individual experiences in the human-environment interaction and adding the element of transaction (Batorowicz et al. 2015). Transaction in this case refers to individuals, who by own choices, active engagement and collaboration in various settings, affect their social environment. The effect can either increase or decrease the usual activity of the individual, alternatively elicit or initiate a new response. The contributions of these models can help researchers and practitioners to better understand the complexity of how individuals are linked with the environment, and as such facilitate better health outcome for individuals with disabilities.

1.2 NEURODEVELOPMENTAL DISORDERS

Neurodevelopmental disorders (NDD), with an estimated prevalence of 10-15 % in the general population (Boyle et al. 2011), are a group of brain-based conditions that share certain commonalities that are distinguished from other types of psychiatric conditions. Indeed, unlike the remitting and relapsing pattern of symptoms that are prominent in many mood and anxiety disorders after puberty, NDD typically onset in early childhood, usually before puberty, with life-long patterns of neurocognitive symptoms (i.e. global intelligence, social cognition, psychomotor functions, attention, memory) that tend to persist into adulthood, despite being subjected to maturational changes (Thapar, Cooper & Rutter, 2017). NDD are usually more common in males and there is a high heritability, albeit these are typically multi-factorial in origin with no distinct biological marker or pathway that separates the conditions. The conditions are instead categorized into discrete diagnostic entities based on their clinical presentation, which can be a bit challenging, given that there is a high overlap between the various types of NDD (Matson & Shoemaker, 2009; Rosen, Mazefsky, Vasa & Lerner, 2018). The latter, however, supports the rationale for grouping these conditions into one larger entity. It's important to note that the clinical presentation of NDD can vary considerably from one individual to another, which is why assessment and treatment of NDD usually require multiple specialists (i.e. psychologists, psychiatrists, pediatricians, occupational therapists, speech pathologists) across different agencies (i.e. psychiatry, habilitation, rehabilitation, education). Today, there is a wide consensus among researchers and experts that NDD are not curable and should therefore be viewed as extreme ends of variations in functioning (Bölte, 2014; McLennan, 2016). This shift in how NDD is conceptualized makes non-morbid outcomes, such as functioning, participation, well-being and quality of life, vital components to address in order to understand health experiences of individuals with NDD.

1.3 ATTENTION-DEFICIT/HYPERACTIVITY DISORDER AND AUTISM SPECTRUM DISORDER

1.3.1 Diagnostic criteria

Attention-Deficit/Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) are two conditions that are part of the NDD group. ADHD is composed of the core symptoms "inattention, impulsivity and hyperactivity", whereas ASD is characterized by "deficits in social communication and interaction, alongside repetitive, restricted behavior patterns and interests" (APA, 2013, p. 31-32). The recent release of Diagnostic Statistical Manual of Mental Disorders -fifth Edition (DSM-5) marked a couple of modifications in how ADHD and ASD are diagnosed compared to previous versions of DSM. In ADHD, the number of symptoms required for a diagnosis in adulthood has been reduced from six to five, and the onset of symptoms and impairments have changed from <7 years of age to onset before age 12. Furthermore, the term subtypes have been replaced with a new system that encompasses rating the severity of core symptoms and accompanying impairments according to a three-point scale (i.e. mild, moderate and severe). Additional changes include removing ASD as an

exclusionary diagnosis and requiring functional impairments to reduce the quality of social, occupational and academic functioning. When it comes to ASD, one umbrella diagnosis, Autism Spectrum Disorder (ASD), was conceptualized in DSM-5, replacing the previous version which divided ASD into three different subtypes, namely Autistic Disorder (i.e. nonverbal children or children who showed delay in language development), Asperger's syndrome (i.e. higher functioning individuals with no substantial delay in language development) and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS; i.e. individuals who had atypical/subthreshold symptomatology or late onset of symptoms, or all of these). The DSM-5 also merged social reciprocity and communication into one entity. Another key difference is related to onset of symptoms, with DSM-5 removing the age specification by acknowledging that symptoms might not fully be recognized until social demands exceed capacity. Furthermore, the DSM-5 requires functional impairment to be present in social, occupational, or other areas of life. Moreover, the DSM-5 requires professionals to specify severity level of behavioral symptoms according to a three-point scale, hence marking a paradigm shift towards a more dimensional perspective on ASD. A new diagnosis was introduced in DSM-5 (i.e. social communication disorder) to capture individuals who met the criteria of social communication and interaction difficulties, but not repetitive, restricted behavior patterns. The DSM-5 also stressed the importance of examining sensory sensitivity in ASD by including it as part of the core symptom criterion repetitive, restricted behavior patterns and interests.

While the DSM is used as reference tool for diagnosing psychiatric conditions in North America, the International Statistical Classification of Diseases and Related Health Problems (ICD) is widely used in Europe (WHO, 1992; WHO, 2018). In 2018, the ICD-11 was published, which introduced certain revisions to ADHD and ASD. For example, the term ADHD was used in the ICD-11 for the first time, replacing the former term hyperkinetic disorder. The exclusion criteria for ADHD in ICD-11 were also modified, using less strict rules to diagnose ADHD by removing mood and anxiety disorders as well as schizophrenia as exclusionary diagnoses. In the previous version of ICD, the age of onset of ADHD was explicitly mentioned to be before age of 6, whereas the current version does not specify the exact age, but instead states that the onset should happen somewhere during the developmental period, between early to mid-childhood. Finally, the ICD-11 emphasizes functioning impact as an important criterion for ADHD, stressing that symptoms must cause significant disruptions in functioning across academic, occupational, or social life. Regarding ASD, the ICD-11 has followed a similar path as DSM-5, clustering the different subtypes of ASD (i.e. Autistic disorder, Asperger's syndrome etc.) into one larger entity (i.e. Autism Spectrum Disorder). Unlike its predecessor ICD-10, language problem has been removed as separate criterion for ASD, leaving two core symptom criteria to assess, much like the DSM-5. Furthermore, the ICD-11 has removed the age specification for onset of symptoms in ASD, recognizing that symptoms may be manifested at later stage in childhood when social demands exceed limited capacities. Functioning impact is also acknowledged in ICD-11. Although the DSM-5 and ICD-11 share many similarities with regards to diagnostic

assessment of ADHD and ASD, they still differ in a number of ways. Firstly, ASD is regarded as an exclusionary diagnosis for ADHD in ICD-11, which is not the case in DSM-5. Secondly, ICD-11 provides detailed guidelines for distinguishing autism with and without intellectual disability, contrary to DSM-5, which only remarks that these two conditions can co-occur.

1.3.2 Prevalence

The prevalence of ADHD and ASD varies considerably. In 2007, a systematic review estimated the worldwide prevalence for ADHD to be 5 % in children and adolescents (Polanczyk, de Lima, Horta, Biederman & Rohde, 2007). In 2012, a new review was published, which found the prevalence rate of ADHD in children and adolescents (<18 years of age) to range from 6 to 7 % (Willcutt, 2012), followed by another review which showed a slightly higher prevalence rate of 7.2 % (Thomas, Sanders, Doust, Beller & Glasziou, 2015). The increase in ADHD diagnosis is well-documented, as evidenced by a Swedish study which found the annual prevalence rate of Swedish patients with ADHD to be 1.1 per 1000 persons in 2006, whereas in 2011, the number had reached 4.8 per 1000 persons, with more than fourfold increase (Giacobini, Medin, Ahnemark, Russo & Carlqvist, 2018). Same study found the prevalence rate of newly diagnosed patients with ADHD increasing from 0.6 per 1000 individuals in 2007 to 1.3 in 2011. In a recent report from 2016, it was estimated that the prevalence rate of children and adolescents with ADHD in Stockholm County was 2 % and 7.7 %, respectively (CES, 2017). The corresponding prevalence rate for adults with ADHD (>18 years of age) was 5.6 %, which is in stark contrast to the lower prevalence rates that have been reported in the past, ranging from 2.5 to 4.4 % (Fayyad et al. 2007; Kessler et al. 2006; Simon, Czobor, Bálint, Mészáros & Bitter, 2009). A similar shift in prevalence rate has also been found in ASD in the past decade, with previous studies estimating the prevalence rate of ASD in children and adolescents to range between 0.4 to 1 % (Baird et al. 2006; CDC, 2008), differing from more recent reports showing the prevalence rate to almost approach 2 % (CDC, 2016; Idring et al. 2015). Remarkably, a Swedish cohort study found the prevalence rate of children and adolescents with ASD to increase by almost 3.5-fold, from 0.4 % in 2001 to 1.4 % in 2011 (Idring et al. 2015). In 2016, the prevalence rate of children and adolescents diagnosed with ASD in Stockholm County was estimated to be at 1.4 % and 3.1 %, respectively (CES, 2017). A steady increase in ASD diagnosis has also been observed in adults. For instance, Brugha et al. (2011) found the prevalence rate of adults with ASD to be at almost 1 % in 2007, which is significantly lower than the 2.4 % that was reported ten years later in Stockholm County (CES, 2017).

The increase in ADHD and ASD diagnosis can be attributed to multiple factors. One explanation could be that there is a greater awareness and knowledge of the conditions among different stakeholders in society, hence resulting in better access to healthcare and improved quality care (Rydell, Lundström, Gillberg, Lichtenstein & Larsson, 2018). Another theory could be the usage of more robust diagnostic tools that enable symptoms to be detected earlier (Rice et al. 2013). The increase in diagnosis could also be related to the fact that there

may be greater expectations from society to manage everyday life activities with social demands exceeding one's own capacity and resources, which may in turn cause individuals to get referred for neuropsychiatric evaluations (Rydell et al. 2018). Other researchers attribute the considerable variation in prevalence rates to studies applying different methodology to assess ADHD and ASD, with some using ICD-criteria, which applies stricter guidelines to diagnose conditions (Polanczyk, Willcutt, Salum, Kieling & Rohde, 2014). Consequently, lower prevalence rates are expected to be found for those specific meta-studies. Furthermore, assessments could vary from studies to studies, with some accounting for impairment of symptoms, whereas others may neglect this, thus resulting in significant higher rates of diagnosis (Rydell et al. 2018). Another hypothesis is that the increase in diagnosis may reflect a true increase in diagnostic traits. However, studies have shown that the prevalence of traits remain stable over time, even though diagnosis of ADHD and ASD has increased (Lundström, Reichenberg, Anckarsäter, Lichtenstein & Gillberg, 2015; Rydell et al. 2018), which suggests that the increase in diagnosis is rather related to external causes (e.g. changes in diagnostic assessment, greater awareness, etc.).

1.3.3 Etiology

Twin studies estimate high heritability of ADHD (~75 %) across the entire lifespan (Larsson, Chang, D'Onofrio & Lichtenstein, 2014; Schachar, 2014), regardless of whether ADHD is assessed as a disorder (diagnosed vs. non-diagnosed) or as an extreme end of a normal distribution (more or less hyperactive, inattentive and impulsive). Environmental influences are estimated to be low to moderate, but studies show significant correlations between early risk factors (e.g. premature birth, low birth weight, prenatal tobacco exposure) and later development of ADHD symptoms (Froehlich et al. 2009; Galéra et al. 2011; Heinonen et al. 2010). On a neural level, children with ADHD seem to exhibit delay in the peak of cortical thickness maturation, with the greatest delays found in regions related to frontal and temporal structures (Nakao, Radua, Rubia & Mataix-Cols, 2011). Dysfunction in these parts of the brain might therefore underlie the cognitive problems that individuals with ADHD experience in daily life, e.g. inattention, impulsivity, motor restlessness and motivation deficit (Barkley, 1997). The cortical delays are widely believed to affect specific neurotransmitters in the brain, particularly dopamine, which is known for its role in cognition, motor activity and motivation (Genro, Kieling, Rohde & Hutz, 2010). Some critics, however, question the dopamine hypothesis for not taking into account interindividual differences in ADHD symptoms and functioning level (Sonuga-Barke, 2003). The Sonuga-Barke's dual-pathway model tries to address this issue by suggesting that there are two separate pathways to ADHD symptoms. The first pathway is characterized by executive dysfunction, positing that dysfunctional activity pattern in the frontal lobe causes a range of cognitive problems, including inhibition and attention. The second pathway is delay aversion, hypothesizing that deficits in basal ganglia cause individuals with ADHD to be hypersensitive to delay, experiencing difficulties in waiting for rewards and working effectively over extended time periods. In recent years, a third pathway has been added to the model, namely time delay (Sonuga-Barke, Bitsakou & Thompson, 2010).

Similar to ADHD, ASD is associated with high heritability, with findings supported by twin studies dating back to the 1970s (Folstein & Rutter, 1977). Subsequent twin studies have since replicated previous findings (Lichtenstein, Carlström, Råstam, Gillberg & Anckarsäter, 2010; Ronald & Hoekstra, 2011; Tick, Bolton, Happé, Rutter & Rijsdijk, 2016). However, the assumption of high heritability has recently been questioned, with studies indicating that ASD is a far more complex condition involving both genetic and environmental influences (Hallmayer et al. 2011; Mandy & Lai, 2016). Various psychological models have tried to explain the social challenges associated with ASD. One such model is the "theory of mind", which posits that individuals with ASD have altered ability to ascribe intents, beliefs and desires to oneself and other people (Baron-Cohen, Leslie & Frith, 1985), and understand that others may have certain convictions, wishes or intentions that differ from oneself. Even though the theory of mind has received some support in research (O'Nions et al. 2014), it does not fully explain other problem areas related to ASD, such as weaknesses in detecting patterns (Frith, 1970), sorting faces by persons (Weeks & Hobson, 1987) and solving jigsaw puzzles by picture (Langdell, 1978). To address these issues, the central coherence theory was developed (Frith & Happé, 1994), hypothesizing that individuals with ASD face problems with sensory integration at different information levels, resulting in limited ability to understand context or to "see the big picture" of events. Recent findings, however, contradict the central coherence theory, leaving the interplay of information processes in ASD only partly understood (Van der Hallen, Evers, Brewaeys, Van den Noortgate & Wagemans, 2015).

1.3.4 Interventions

There is a wide consensus among researchers that there is no cure for ADHD and ASD (Bölte, 2014), even though some studies claim major improvements or even recovery (Fein et al. 2013; Granpeesheh, Tarbox, Dixon, Carr & Herbert, 2009; Lovaas, 1987). These findings must, however, be cautiously interpreted, as they entail several methodological shortcomings that makes it difficult to judge the significance of the results (Bölte, 2014). Methodological shortcomings include lack of comparability of experimental and control groups and using insufficient tools to assess and diagnose the conditions. Moreover, the notion of curing ADHD and ASD or achieving recovery is very unfamiliar among researchers in the field, limiting possibilities of drawing any conclusions on what recovery really entails. Given that NDD are today viewed as extreme ends of traits in a normal distribution rather than group of curable conditions (Bölte, 2014; McLennan, 2016), interventions in ADHD and ASD are primarily focused on ameliorating symptoms and increasing functioning status and quality of life (National Institute for Health and Care Excellence, 2018; Volkmar, Paul, Rogers & Pelphrey, 2014).

Aside from strategies of adapting the environment to the needs of individuals, multimodal treatment is recommended in ADHD (Socialstyrelsen 2014a). Herein, stimulant medications are currently the pharmaceutical treatment of choice in ADHD (Bitter, Angyalosi & Czabor, 2012; Chan, Fogler & Hammerness, 2016; Storebø et al. 2015). The stimulant

methylphenidate acts as a dopamine reuptake inhibitor, increasing the level of the neurotransmitter in the brain. Atomoxetine, a Serotonin-norepinephrine reuptake inhibitor (SNRI), is another first-choice medication commonly used in the treatment of ADHD (Savill et al. 2015). Besides medication, there are other types of interventions that are offered in ADHD. These include (i) behavior therapy, which aims to selectively reinforce desired behaviors and ignore problem behaviors, (ii) direct skills training, which involves teaching specific skills (e.g. organization, time management) to manage common ADHD-related deficits, (iii) cognitive behavioral therapy (CBT), which consists of identifying negative or automatic thoughts and modifying them through different techniques (e.g. mindfulness), and (iv) neurofeedback training, which aims to enhance specific attentional states based on principles of operant conditioning (Chan et al. 2016; Sibley, Kuriyan, Evans, Waxmonsky & Smith, 2014; Sonuga-Barke et al. 2013). Despite the inconsistent effects of psychosocial interventions on ADHD symptoms, greater improvements in academic and organization skills have been reported.

Contrary to ADHD, to date, there are no available evidence-based pharmacological interventions for treating ASD core symptoms (DeFilippis & Wagner-Dineen, 2016; Hsia et al. 2014), which has led researchers to shift focus towards non-invasive behavioral interventions that target different aspects of outcome, ranging from ASD symptoms and cognitive abilities to adaptive behaviors and functioning (Choque-Olsson et al. 2017). Recent reviews of autism interventions, which include intensive behavioral interventions, parent-mediated early interventions and social skills training, found low to moderate efficacy (Gates, Kang & Lerner, 2017; Weston, Hodgekins & Langdon, 2016). The quality of the studies varies quite considerably, indicating a further need for intervention research that can provide more robust conclusions. Indeed, the urgent call for evidence-based interventions has persuaded the research community to advocate for services that could be offered in different settings to improve functioning level and quality of life of individuals with ASD (Fein, Barton & Dumont-Mathieu, 2017; Fleury et al. 2014; van Schalkwyk & Volkmar, 2017).

1.3.5 Impact on individual health

Based on the WHO's definition of health as a state which does not only include absence of illness or disease, but also well-being in physical, mental and social domains (WHO, 2014), as well as ability to cope with environmental demands and meet own needs and aspirations (WHO, 1984), one can conclude that the concept of health in ADHD and ASD contains multiple dimensions that touch upon various aspects of health. Psychopathology is one such dimension, exploring symptom complaints and mental impairments in individuals (WHO, 1992). Quality of life (QoL) is another dimension, referring to the subjective perception of health, i.e. how individuals experience their own position in life in relation to their goals, expectations and living standards (WHO, 1997). Functioning is the third dimension, capturing the objective reality of individuals, specifically how individuals are engaging in everyday life situations and performing activities of daily living in relation to environmental

demands (WHO, 2001). Although the dimensions differ from each other conceptually, they interact with one another in real life, influencing overall experiences of health.

1.3.5.1 Psychopathology

Comorbidity in ADHD and ASD is substantial. Using cross-sectional and longitudinal data, Michielsen et al. (2013) found depressive and anxiety symptoms to be persisting in older adults with ADHD, even though respondents reported fewer core symptoms over the years. Similar results have been found in the ASD population as well (Joshi et al. 2013; Salazar et al. 2015). Externalizing behavior problems, such as conduct disorder and oppositional defiant disorder, are also highly prevalent among individuals with ADHD or ASD (Ahmad & Hinshaw, 2017; Salazar et al. 2015; Simonoff et al. 2008). Intellectual disability is another condition that can be found in the population with NDD (Cervantes & Matson, 2015). In fact, researchers have estimated that as much as 40 % of individuals with intellectual disability also have a diagnosis of ASD (Matson & Shoemaker, 2009). The co-occurrence of ADHD and ASD has not been widely investigated in research, given that previous versions of diagnostic systems regarded ASD as exclusionary diagnosis for ADHD and vice versa. Population-based prevalence, however, indicates that 21-30 % of younger individuals with ASD also have a diagnosis of ADHD (Rosen et al. 2018). Although psychiatric comorbidity in ADHD and ASD is well-documented, the exact mechanisms underlying co-occurring conditions remain unclear. It could for instance be that there is a "true" comorbid condition that requires separate treatment, or that certain symptoms of a condition (e.g. social avoidance in ASD) produce similar symptom presentation reminiscent of another co-occurring condition (e.g. social anxiety). Even though ADHD and ASD are conceptualized as brain-based conditions, the impact stretches beyond neurocognitive symptoms to influence other body processes. Indeed, plethora of research studies suggest physical impairments to be prevalent in ADHD and ASD (Dufek, Eggleston, Harry & Hickman, 2017; Instanes, Klungsøyr, Halmøy, Fasmer & Haavik, 2018; Lyall, Van de Water, Ashwood & Hertz-Picciotto, 2015; McElhanon, McCracken, Karpen & Sharp, 2014; Niemczyk, Equit, Hoffmann & von Gontard, 2015; Travers, Powell, Klinger & Klinger, 2013), which include motor-related difficulties (e.g. postural instability, gait pattern deviation), gastrointestinal complications (e.g. constipation, incontinence) and immunological deficits (e.g. allergy, asthma). Individual traits of ADHD and ASD have also been found to negatively correlate with QoL (Danckaerts et al. 2010; Mason et al. 2018), although some studies dispute this (de Vries & Geurts, 2015). The relationship between symptom severity and functioning level is not fully established, as evidenced by a longitudinal study conducted by Howlin and colleagues (2013) which showed social inclusion in adults with ASD to remain poor, even though symptoms improved over time. Similar findings have also been discussed in ADHD literature (Simon et al. 2009), leading researchers to conclude that health is a state that extends beyond symptom complaints and psychopathology.

1.3.5.2 Quality of life

Children and youth with ADHD and ASD experience poorer QoL compared to typically developing individuals (Jonsson et al. 2017), with similar tendencies persisting into adulthood (Lensing, Zeiner, Sandvik & Opjordsmoen, 2015; van Heijst & Geurts, 2015). Outcome in QoL can nevertheless differ on individual basis depending on multiple factors. Facilitators in the environment, such as parental commitment and peer support, can increase QoL in individuals with ADHD and ASD, whereas barriers, such as peer conflicts and parental separation/divorce, can decrease outcome (Jonsson et al. 2017). For older individuals, spousal support can play an important role in QoL (Brod, Schmitt, Goodwin, Hodgkins & Niebler, 2012). Additional factors that seem to influence QoL in ADHD and ASD are presence of co-existing psychiatric problems (Knüppel, Kjaersdam Telléus, Jakobsen & Lauritsen, 2018; Schei et al. 2016) and level of functioning status (Lensing et al. 2015; Mason et al. 2018). Indeed, studies have shown that being employed, having a relationship and participating in community activities are significant predictors of positive QoL in individuals with ADHD and ASD (Lensing et al. 2015; Mason et al. 2018). Other factors that seem to correlate with QoL are personal factors such as gender and residence. Mason et al. (2018) reported that females with ASD scored lower in most domains of QoL than males, while Knüppel et al. (2018) found living situation, such as living with parents and living independently with support, to be associated with lower QoL in adults with ASD.

1.3.5.3 Functioning

Adaptive functioning refers to set of skills that are necessary in order to live an independent and self-governing life (APA, 2013). Limited adaptive functioning makes it difficult to successfully transition in life and achieve age appropriate standards of behavior. This can clearly be seen in academia, where individuals with ADHD or ASD struggle with school-related responsibilities, failing to advance to other stages of education and complete a degree (Fredriksen et al. 2014; Levy & Perry, 2011). Consequently, poorer occupational outcome is often reported in the ADHD and ASD population, causing significant burden for both the individual and society (Baldwin, Costley & Warren, 2014; Gjervan, Torgersen, Nordahl & Rasmussen, 2012). Socially, ADHD and ASD are correlated with increased risk of marital failure, having less contact with family and friends, and emotional loneliness (Mazurek, 2013; Michielsen et al. 2015). Moreover, individuals with ADHD and ASD tend to have limited engagement in activities of enjoyment (Michielsen et al. 2015; Ratcliff, Hong & Hilton, 2018). Notwithstanding the extensive impact on functioning, individual strengths have also been identified in both conditions. Hyper-focus has been reported in ADHD, with individuals experiencing intense focus in intrinsically rewarding activities (Hupfeld, Abagis & Shah, 2018). Creativity is another area that has been implicated in ADHD, although with mixed research results (Healey & Rucklidge, 2005). Recent findings, however, suggest that adults with ADHD tend to generate more original ideas than non-diagnosed individuals when competing for rewards (Boot, Nevicka & Baas, 2017). Another strength observed in ADHD is entrepreneurial intentions, which could partly be explained by individuals' propensity to take higher risks (Verheul et al. 2015). Regarding ASD, Iuculano et al. (2014) found superior

numerical problem-solving abilities in diagnosed children compared to typically developing individuals. Other talents identified in ASD include attention to detail (Baron-Cohen, Ashwin, Ashwin, Tavassoli & Chakrabarti, 2009) and visual ability (Nilsson-Jobs, Falck-Ytter & Bölte, 2018), as well as recognizing repeating patterns in stimuli (Baron-Cohen et al. 2009) and having increased auditory capacity (Remington & Fairie, 2017). Although employment rate in ASD is low, a study identified supervisors to rate individuals with ASD highly on multiple factors relevant to job performance (e.g. loyalty, punctuality, low absenteeism) (Hillier et al. 2007), indicating that autistic individuals can be competitive in entry-level jobs. The considerable variation in functioning outcome in ADHD and ASD can partly be attributed to presence of facilitatory environmental influences. Indeed, provision of emotional support (e.g. parental involvement, positive peer influence), positive attitudes (e.g. acceptance, knowledge) and availability of services and programs (e.g. transportation, counselling, evidence-based programs) have all been indicated as important factors for increasing functioning status in ADHD and ASD (Askari et al. 2015; Brewster & Coleyshaw, 2010; de Boer & Pijl, 2016; Ray, Evans & Langberg, 2017). Higher independent skills among individuals with ADHD and ASD have also been found to predict more favorable outcome in social functioning and participation (Humphreys, Galán, Tottenham & Lee, 2016; Liptak, Kennedy & Dosa, 2011). Social participation (e.g. joining community activities and engaging in festivities) in turn has been deemed a significant predictor of QoL in individuals with ADHD and ASD (Ray et al. 2017; Schmidt et al. 2015), serving as a protective factor against secondary problems such as social exclusion, depression, anxiety and substance abuse (Lounds Taylor, Adams & Bishop, 2017; Wehmeier, Schacht & Barkley, 2010). Participation in social activities has also been found to enhance outcome in social functioning in terms of learning how to create and maintain friendships (Dovgan & Mazurek, 2019). The results here underpin the importance of assessing functioning in order to understand and improve outcome in ADHD and ASD.

1.4 CLINICAL GUIDELINES AND ASSESSMENT OF ADHD AND ASD

1.4.1 Clinical guidelines

The clinical assessment of ADHD and ASD serves multiple purposes (BUP SLL, 2015; National Institute for Health and Care Excellence, 2018; Volkmar et al. 2014). One is to determine whether a person has a diagnosis or not. Another is to identify areas of challenges and difficulties that can be targeted with intervention. A third aim is to assess and evaluate interventions. Given the complexity of ADHD and ASD in terms of clinical presentation and development (Thapar et al. 2017), national and local clinical guidelines recommend assessment to be made by interdisciplinary healthcare professionals specialized in ADHD and ASD (BUP SLL, 2015; National Institute for Health and Care Excellence, 2018; Socialstyrelsen, 2014b; Volkmar et al. 2014). The assessments should involve a close collaboration with the client and caregivers, as well as comprise information from multiple informants and sources rather than relying on results from single test scores or rating scales. Appropriate referrals should be made in cases where individuals present certain types of

behaviors or challenges that are more pertinent to be addressed by other agencies. Results from assessments must be communicated according to the knowledge level of caregivers and individuals and the information should be provided in a way that supports them in finding appropriate care and service. When planning interventions, it is essential that professionals target different aspects of individual health (i.e. symptoms, functioning, QoL). The interventions should also be adapted to match individual resources and set goals that are coherent with individual needs. For adults, it is strongly advised that they get assessed in a separate clinic. To facilitate transition in care, there needs to be a protocol or system in place that enables important information to be communicated across different service providers. Referral to adult services are usually made when persisting ADHD and ASD-related symptoms are suspected to interfere with QoL and functioning across social, educational and occupational domains. Although the clinical assessment of ADHD and ASD can vary a bit depending on individual age and functioning level, the procedure usually includes i) a full account of the individual's developmental and psychiatric history (including environmental factors), ii) a medical examination, iii) a neuropsychological evaluation and iv) a written assessment report.

1.4.2 Clinical assessment

The clinical assessment of ADHD and ASD usually starts with medical history taking, examining individual development (i.e. motor, cognition, social, perception, communication), maternal risk factors (i.e. smoking during pregnancy, infection, alcohol consumption), heredity (i.e. psychopathologies, somatic issues) and psychosocial environment (i.e. family dynamics, living setting, socioeconomic status) (BUP SLL, 2015; National Institute for Health and Care Excellence, 2018; Volkmar et al. 2014). Interviews with caregivers are integral to this phase, along with records transferred from preschool or school. Questionnaires screening for ADHD and ASD symptoms are provided and completed by clients, caregivers and teachers. A medical examination is performed to check for somatic, sensory and neurological/motor status, and if necessary, referrals are made to neurologists, audiologists, speech-language pathologists, physiotherapists or occupational therapists. If suspicions of ADHD and ASD remain, a neuropsychological evaluation is ordained consisting of a comprehensive assessment of behaviors and core symptoms manifested in various settings (e.g. home, school, leisure). A vital part includes establishing weaknesses and strengths in individuals (i.e. adaptive skills), checking for overall levels of cognitive ability (i.e. IQ) and assessing environmental settings of clients (e.g. home, school). Additional goals include investigating comorbidity and functioning status. A wide range of tools, ranging from semi-structured interviews (e.g. Autism Diagnostic Interview-Revised [ADI-R]) and observation schedules (e.g. Autism Diagnostic Observation Schedule -second edition [ADOS-2]) to performance-based tests (e.g. The Conners Continuous Performance Test -third edition [CPT-3]; Delis-Kaplan Executive Function System [D-KEFS]; Wechsler Intelligence Scale for Children -fifth edition [WISC-V]) and self and proxy reports (e.g. Behavior Rating Inventory of Executive Function [BRIEF]; The Conners-3, Social Responsiveness Scale [SRS]) are used to assess core symptoms and cognition. Certain tools (e.g. Adaptive Behavior

Assessment System -second edition [ABAS-2], Vineland Adaptive Behavior Scale [VABS]) are usually administered to explore level of adaptive functioning, investigating necessary skill sets required to navigate oneself across different domains of functioning, including communication, social, physical and self-care domains. Widely established tools such as Global Assessment of Functioning (GAF) and Children's Global Assessment Scale (C-GAS) are administered to check for functioning impact, measuring how an individual's symptom level may influence his or her everyday life functioning on a scale from 0 (needs constant supervision 24/7) to 100 (superior functioning in all areas), providing clinicians and practitioners a crude estimation on severity of functioning impact which can be useful for assessing overall functioning status. Once the neuropsychological assessment has been concluded, a meeting is scheduled with the client and caregivers to discuss the results found in the entire assessment procedure. A written assessment report is usually provided, summarizing the results from the clinical assessment and informing stakeholders about targets for intervention. The report also includes information on available services that caregivers and clients can apply for.

1.4.3 Limitations in clinical assessment of ADHD and ASD

Despite recent advances in availability of standardized assessment tools for ADHD and ASD, there are some limitations that invites to closer examination. One limitation concerns the lack of standardized, well-established tools that assess functioning impact in clinical practice (Bölte et al. 2014a; Bölte et al. 2014b; Huerta & Lord, 2012; Zander & Bölte, 2015). While current tools (e.g. C-GAS, GAF, Vineland-II, ABAS-2) help clinicians and practitioners to establish a crucial starting point for making a clinical diagnosis, the utility of these tools may be questioned for intervention purposes, as these are deemed too general to capture concrete challenges in everyday life (Castro, Ferreira, Dababnah & Pinto, 2013; Gleason & Coster, 2012). Indeed, assessing overall functioning status may be appropriate for confirming diagnosis, but not for intervention planning, which usually requires comprehensive assessments that can account for individual differences in functioning profile. Diagnosis alone cannot predict outcome, as one individual may present an entirely different profile of functional limitations and strengths compared to another person (Castro & Pinto, 2015). The importance of functioning is further highlighted by the fact that current diagnostic systems have introduced impairment as a mandatory diagnostic criterion in ADHD and ASD, meaning that a diagnosis cannot be made without accounting for functioning impact. This is not a surprising development, considering that functioning impairments most often constitute the primary cause for initial referral to services (Bölte et al. 2014a; Bölte et al. 2014b). In fact, service-related costs are usually predicted by level of impairment (Wade & Halligan, 2017), which further supports the need for comprehensive assessments that can generate accurate calculation of health-related costs. The lack of standardized tools for functioning assessments is rather remarkable, given the wide consensus among researchers and practitioners that ADHD and ASD are life-long conditions that persist into adulthood, causing significant disruptions in everyday life functioning. Since functioning is widely viewed as an important dimension of health (WHO, 2001; WHO, 2007), current guidelines

must entail proper assessments of functioning to better predict health outcome in ADHD and ASD. The usage of such tools would enable stakeholders to better understand behavior problems as a whole, complementing categorical descriptions of symptom experiences with vital information on individual functioning (Bölte et al. 2014a; Bölte et al. 2014b). The information on functioning could subsequently facilitate interventions that are more in line with individual goals and demands. Indeed, what individuals with ADHD or ASD prefer in terms of care and assistance could differ from what the professionals and general society expect (van Schalkwyk & Volkmar, 2017), which is why it is important to ensure that clients and caregivers are actively involved in assessment and intervention planning. However, evidence suggests that some family members and individuals with ADHD and ASD feel excluded in issues concerning healthcare support and personal needs (Swedish Council on Health Technology Assessment, 2013a; 2013b), contradicting current assessment guidelines on inclusion and close collaboration (BUP SLL, 2015; National Institute for Health and Care Excellence, 2018). One reason for this discrepancy could be that there is a shortage of assessment tools that capture personal and environmental influences on health outcome. The former may include factors that are inherent to the individual, but nevertheless important for outcome improvement, such as intrinsic motivation and compliance, whereas the latter may encompass certain factors in the social environment that either increase or reduce patient experience depending on quality of support. The limited availability of assessment tools that capture environmental influences may be rooted in the medical model's dominance in psychiatry. Indeed, an overwhelming majority of assessment tools used in ADHD or ASD focuses on capturing individual traits rather than exploring environmental factors (Castro et al. 2013), contradicting the plethora of research studies highlighting the importance of environmental influences on long-term outcome in ADHD and ASD (Askari et al. 2015; Brewster & Coleyshaw, 2010; de Boer & Pijl, 2016; Ray et al. 2017). By applying a biopsychosocial approach, it would help clinicians and practitioners to see the individual from a holistic perspective, assessing information on core symptoms and behavioral challenges with much needed descriptions about facilitators and barriers in the environment. Another advantage with assessing environmental influences is that it could facilitate interventions that use inclusive-oriented approaches to enhance functioning, which deviates from many of the current programs in ADHD and ASD which aim to target individual impairments by changing behavior patterns or teaching new skills (Gates et al. 2017; Scott et al. 2018; Sonuga-Barke et al. 2013). Such interventions may be viewed more stigmatizing and less motivating for clients and caregivers.

Additional gaps in assessment concern the lack of emphasis on capturing individual strengths in ADHD and ASD (Bölte et al. 2014a; Bölte et al. 2014b). Given that previous research indicate certain skill sets to be associated with ADHD and ASD (Hupfeld et al. 2018; Nilsson-Jobs et al. 2018), it is important that these do not get overshadowed by assessment of behavioral challenges. The information on strengths can be equally useful, as it can provide the basis for interventions that aim to reinforce individual skill sets and resources (Bölte et al. 2014a; Bölte et al. 2014b). Other criticisms pertain to the transition phase from child and

adolescent psychiatry to adult care. A large European review study found that many services specialized in child and adolescent psychiatry lacked proper transition channels to adult care (Ginsberg, Beusterien, Amos, Jousselin & Asherson, 2014), which is remarkable given that the transition from adolescence into adulthood is usually marked as a tumultuous period with increased expectations on individual responsibility and independence. The burden of dealing with increasing demands combined with lacking proper transition care could result in serious personal consequences. A lack of awareness of adult services among healthcare professionals as well as inadequate knowledge and expertise about NDD in adulthood have been identified as significant barriers to a successful transition phase. Finally, some criticisms have been levelled against the lack of specificity in the current DSM-5 impairment criterion (Zander & Bölte, 2015), which explicitly calls for healthcare professionals to specify the level of support required in ASD (1 = requiring support, 3 = requiring very substantial support). The criterion does not offer any further explanation for how support should be provided nor what areas of functioning that should be investigated. By using a framework specifically designed to describe functioning from a biopsychosocial perspective, it could help professionals to take all aspects of an individual's life into account and as such generate information that can be useful to identify concrete areas of support.

1.5 INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

1.5.1 History and framework

In 1853, the first international congress took place in Europe to discuss the needs for a classification system that described causes of mortality (Jetté et al. 2010). Forty years later, the International List of Causes of Death (ILCD) was published to report on mortality and subsequent causes of death. Attempts were made to create a parallel list of morbidities and diseases, but these failed to receive wider attention until 1948, when the WHO officially adopted the International Statistical Classification of Diseases (ICD) as a reference tool for coding morbidity in addition to mortality. Since its inception in 1948, the ICD has undergone multiple revisions and is today regarded the leading international system for classifying symptom complaints, disorders, diseases and external causes of injuries. While the ICD has provided users with concrete means to classify and monitor diseases and disorders, it has been criticized for failing to integrate the human experience of having a health condition. Indeed, following advances in medical research and improved living standard, the focus of treatment has shifted from acute illness to managing chronic conditions in society. Hence, the definition of health has evolved to encompass other vital dimensions deemed important to individuals, but not sufficiently covered by the ICD, such as non-fatal outcomes, including functional health across all areas of life. To address this, the WHO launched the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980, which provided a comprehensive, unifying framework to assess the impact of diseases, injuries or disorders on individual functioning (WHO, 1980). A main objective with the ICIDH was to improve clinical documentation of health-related functioning problems, applying a universal

taxonomy that enabled professionals to describe and measure various settings of individuals living with a specific health condition. Although the ICIDH signified an important advancement in the documentation of health-related functioning from a conceptual and taxonomic standpoint, several concerns were raised against the framework (Simeonsson, Lollar, Hollowell & Adams, 2000), prompting the WHO to adopt a new classification system. In 2001, the International Classification of Functioning, Disability and Health (ICF) was officially launched as a universal classification system to describe health and functioning at both individual and population levels, getting the approval from all 191 WHO member states (WHO, 2001).

The ICF differs in many regards from its predecessor, the ICIDH. Unlike the ICIDH, the ICF classifies functioning and disability according to a biopsychosocial model, which not only recognizes influences of biology (e.g. anatomical structures, body functions) on health-related states, but also attributes functional outcome to psychological (e.g. behaviors, mood) and social factors (attitudes, family, services). Furthermore, the ICF acknowledges that outcome is based on a reciprocal interplay between the health condition of the individual and contextual factors, replacing the linear relationship that was previously endorsed in the ICIDH. Health and well-being are conceptualized in the ICF into two parts: (i) functioning and disability and (ii) contextual factors (WHO, 2001, 2007). Functioning and disability comprise the components body functions (i.e. physiological functions of the body system, including mental functions), body structures (i.e. anatomical parts of the body), activities (i.e. execution of tasks) and participation (i.e. involvement in life situations), whereas contextual factors consists of environmental (external factors of the individual, e.g. family, attitudes, laws, services) and personal factors (internal factors of the individual, e.g. age, sex, personal attitudes, ethnicity).
While the ICIDH defined disability as limited ability to perform an activity due to an impairment, the ICF considers disability to be a broader concept, encompassing impairments (significant deviation or loss in body function or structure), activity limitations (difficulties in executing a task in daily life) and participation restrictions (problems experienced in involvement in a life situation). The ICF also covers functioning, which describes the positive and neutral aspects of the interplay between health condition and contextual factors (environmental and personal factors), meaning that health can be viewed in a dimensional manner, where positive and negative aspects can be denoted. This is a significant improvement from the ICIDH, which utilized a language that only involved negative aspects of health. Indeed, the ICF uses a neutral language to describe different aspects of functional health and contextual factors. Contextual factors are defined in the ICF either as facilitators or barriers. Facilitators pertain to factors in the environment which serve to improve individual functioning and reduce disability through their absence or presence, while barriers have the opposite effect, limiting functioning and creating disabilities.

Each component in the ICF framework is broken down into different chapters, which provide a quick overview of functioning and environmental domains that are represented in the nomenclature. The chapters in turn are composed of categories that are assigned to unique

alphanumeric codes, enabling users to denote information according to three levels of depth, with the third providing the most detailed information on functioning and environment. Each category includes examples and descriptions that provide clarity on what the unique code represents. Notably, personal factors are missing in the ICF coding scheme given their wide variability among cultures, but they are nevertheless recognized as an important component in the framework. In 2007, a child and youth version of the ICF (ICF-CY) was launched to adequately describe functional health across the entire lifespan, including children and youth (WHO, 2007). The ICF-CY comprises all the categories from the ICF with additional codes that are specific to children and youth. It has been agreed to merge the two classifications into one (WHO-FIC Resolution, 2012), which is why the ICF-CY will from now on be referenced as ICF in this thesis. The ICF contains 1685 categories: 531 body functions, 329 body structures, 552 activities and participation, and 273 environmental factors (WHO, 2007).

1.5.2 Application areas

1.5.2.1 Healthcare

The ICF is a classification system that can serve multiple purposes, meaning that it can be applied in different settings and sectors by various stakeholders (Kostanjsek, 2011; Escorpizo, Brage, Homa & Stucki, 2015). Clinically, many healthcare providers have desired for a classification system that captures a holistic perspective on individual health. A major advantage with the ICF is that all aspects of an individual's life (participation, environment, development) are taken into consideration, enabling service providers to form comprehensive profiles of health-related functioning that accounts for interindividual differences in health status rather than relying on categorical descriptions of diagnosis that are less informative and meaningful. Indeed, diagnosis reveals little about one's ability to function and engage in everyday life activities, which is why a joint-use of ICD and ICF is warranted to ensure that clinicians and service providers integrate assessments related to diagnostic status with information on functional health (Selb et al. 2015a). The merits of applying the ICF to assess functioning and disability have increasingly been recognized in the current diagnostic systems used to classify health conditions (APA, 2013; WHO, 2018). For instance, the DSM-5 has replaced the previously endorsed GAF with a new tool that is more detailed and objective, namely the World Health Organization Disability Assessment Schedule 2 (WHODAS 2.0). WHODAS 2.0 is based on the conceptual framework of the ICF and aims to capture an adult's functioning level across six major areas of activities and participation (i.e. cognition, mobility, self-care, social interactions, life activities and participation in society) (Üstün et al. 2010). In ICD-11, there is a supplementary section dedicated to functioning assessments (WHO, 2018), where healthcare professionals can create functioning profiles and evaluate overall functioning status. References are made to WHODAS 2.0 and the Brief Model Disability Survey, which is another ICF-based instrument containing questions derived from the body functions component, investigating mental and sensory functions. Users are also encouraged to utilize the generic set of ICF codes, which consists of 47 categories related to body functions and activities and participation. Unlike the Brief Model

Disability Survey, the generic set of ICF categories do not contain any descriptions of mental and sensory functions. Instead, it describes other areas of body functions, such as musculoskeletal, voice and speech, genitourinary, cardiovascular and digestive functions. From a practical standpoint, further steps have been taken to implement the ICF in healthcare settings. Service providers, particularly workers in rehabilitation and habilitation programs, have used the ICF to document and code functional status information for the purposes of identifying priorities in care and personalizing interventions (Habilitering & Hälsa, 2016; Kostanjsek, 2011). The common language of the ICF enables service providers to implement and use the framework in their daily professional lives more efficiently. In fact, the ICF can serve to enhance communication between various professional groups (Brunani et al. 2015), promoting an interdisciplinary service approach that is desirable for many patients who seek treatment for both psychiatric and physical complaints. One significant barrier to such collaborative approach has been the lack of a common language to document patient records and communicate important findings across professional boundaries (Terner, Lindstedt & Sonnander, 2012), but the ICF can bridge this gap by offering a framework that applies standardized terminologies and concepts to describe individual health. The ICF can also provide clinicians with hands-on system that not only takes individual weaknesses into account, but also strengths and abilities. The focus on strengths can subsequently prompt clinicians to design interventions that are more resource-oriented and less stigmatizing for patients and caregivers (Thompson, Bölte, Falkmer & Girdler, 2018).

1.5.2.2 Education

The ICF framework, which includes social influences on health-related functioning, can encourage stakeholders to stress the responsibility of the environment for outcome improvement and evaluation. In Portugal, a group of researchers used the ICF framework to evaluate individualized education programs for young children with ASD (Castro, Pinto & Simeonsson, 2014). They found that interventions for young children with ASD were mainly focused on individual performances rather than exploring environmental influences, indicating difficulties in shifting paradigm towards a more inclusive-oriented approach of providing support. Another study examined the content of individualized education programs for students with complex communication needs and showed that although considerable environmental factors were considered, less emphasis was on supporting goals with regards to participation, such as engaging in classroom-related activities and leisure (Klang et al. 2016). The ICF's inclusion of participation as important component can enable stakeholders to identify barriers and enhance outcome. The comprehensive coding scheme of the ICF offers professionals concrete means to assess needs in education, focusing on the individual and not the diagnosis. Indeed, a main advantage with the ICF is that it can generate profiles of functioning on individual level, which is highly relevant given that many complex conditions have a heterogeneous impact on individuals (Adolfsson & Simmeborn Fleischer, 2013). Certain research groups have even moved forward and developed instruments based on the ICF framework (e.g. The Communication Supports Inventory -Children & Youth [CSI-SY]) to guide professionals in designing comprehensive educational plans that will target various

individual strengths and limitations (Rowland et al. 2016). The ICF has also been used as a model to teach educators to apply a biopsychosocial perspective when describing problems that students or pupils may experience in school, encouraging a dynamic way of assessing disability and functioning by also taking into account the influences of the environment on school outcome (Sanches-Ferreira, Lopes-dos-Santos, Alves & Silveira-Maia, 2018). Consistent with international and national efforts to appraise individual health from a wider perspective, the ICF has slowly emerged as a promising framework for policy-making of health-related functioning.

1.5.2.3 Policy-making

Prior to the introduction of the ICF in 2001, many practitioners and researchers highlighted the need for policies which involved taking all aspects of individual health into account (WHO, 2001). A particular emphasis was placed on implementing changes in the environment to meet urgent needs of individuals with disabilities, whether it applies to education, healthcare or community life. In 2006, the Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the United Nations to ensure that individuals with disabilities are guaranteed equal access to education, leisure, family life and occupation. To align with the CRPD, Switzerland decided in 2011 to adopt the ICF framework as basis for establishing eligibility to support services in education (Hollenweger, 2011). The new procedure entailed documenting information beyond diagnosis and impairments to include functioning and disability (i.e. activity and participation), and contextual factors (i.e. school and home environment, personal factors), endorsing a rather dynamic perspective on disability where health outcome is determined by the interaction between individual and environmental factors. Similar development has also been made in other countries. Recently, Portugal passed a law that required eligibility for special education services to be determined based on functioning assessments rooted in the ICF framework (Sanches-Ferreira, Silveira-Maia, Alves & Simeonsson, 2018). In Germany, the federal participation law explicitly states the usage of the ICF to determine magnitude of participation restrictions and subsequent support needs for resource allocation purposes (Bundesministerium für Arbeit und Soziales, 2016). In Australia, national guidelines recommend using tools derived from the ICF framework to assess functioning level and needs in individuals with ASD (Whitehouse, Evans, Eapen, Prior & Wray, 2017).

1.5.3 Challenges with the ICF

The implementation of the ICF has caused some controversies concerning the conceptual framework and the linguistic form in which the different aspects of health are presented in the nomenclature. Pfeiffer (2002a, 2002b) argues that it is impossible to find terms that fit all languages and cultures. Zakirova-Engstrand and Granlund (2009) conducted a study to explore the utility of ICF in classifying functioning in an ethnically diverse sample of families to children with disabilities in Kyrgyzstan. Although much of the information could be assigned to ICF categories, the authors concluded that some chapters of environmental factors, namely attitudes and personal support and relationships, have to be modified for

cross-cultural applicability purposes. Suggested modifications included using a new coding scheme that allows users to differentiate and specify personal support relationships even further. Another challenge relates to the absence of personal factors codes in the ICF, and the ambiguity in what is considered as a "personal factor" (Simeonsson et al. 2014). Given the absence of a clarification or coding scheme, it is unclear how personal factors (as part of contextual factors) may impact individual functioning. This constitutes a significant risk for the status of ICF, as it is a standard requirement for any taxonomy to include a clear definition of its components. This ambiguity makes it difficult to understand what personal factors entail and how these are distinct from other health components. The premise of personal factors has therefore been challenged by some researchers in the field. On the other hand, there are those who argue for the significance of personal factors in daily practice, advocating for a new classification system that links personal factors into taxonomy codes (Grotkamp, Cibis, Nüchtern, von Mittelstaedt & Seger, 2012). One argument is that personal factors can optimize patient-centered care, as it enables past experiences, preferences and attitudes of individuals to be documented. Additional challenges pertain to how activity and participation are operationalized in the ICF (Coster & Khetani, 2008; Granlund, 2013). The framework views activity and participation as separate components, but the coding scheme used to describe these two constructs is the same, meaning that there is no consensus on which codes or chapters that are pertinent to activity or participation. This discrepancy makes it difficult for users to collect information, measure outcomes and plan interventions, hence raising doubts about the usefulness of the constructs in appraising individual health. The ICF presents four solutions to measuring activity and participation (WHO, 2001, 2007), which include (a) designating some chapters as activities and others as participation where no overlaps are allowed, (b) keep the same designation, but allow overlaps in particular cases, (c) designate third and fourth-level codes as activity and broader codes (second-level) as participation categories, or (d) designate all chapters as potentially both activity and participation. Some researchers suggest using a third qualifier to separate these two components from each other. Currently, the ICF recommends using two qualifiers to measure activity and participation, namely capacity (i.e. an individual's inherent potential for actions and execution) and performance (i.e. what the individual does in his or her environment), but Granlund et al. (2012) argues for the inclusion of a third qualifier involving the individual's subjective experience of involvement as outcome measure to participation. Indeed, the ICF's definition of participation does not account for the individual's own sense of involvement, but rather his or her attendance. By this logic, a person who is attending a banquet would be viewed as someone who is participating in an event, regardless of whether the person feels involved in the situation or not. The inclusion of a third qualifier would enable users to differentiate activity from participation in an easier manner, while at the same time ensuring that all aspects of participation are taken into account. However, this option of measuring participation in the ICF has yet to be endorsed by the WHO and ICF Research Branch. Another challenge relates to the interactive biopsychosocial framework of the ICF. Although the ICF acknowledges health and well-being as outcome of an interaction between the individual and environment, it does not offer any explanation of the relationship that takes

place between the different components nor how these may influence one another (Magasi et al. 2015). Failure to understand this will make it difficult for users to identify and describe how environmental factors may impact individual functioning. Finally, the ICF has been criticized for lacking specificity (Stucki, Ewert & Cieza, 2002). Even though the ICF provides a comprehensive framework to capture health-related functioning, to use all 1685 categories would be time-consuming, infeasible and even unnecessary when dealing with individuals with specific conditions. Therefore, the development of ICF Core Sets been mentioned as an approach to facilitate the implementation of the ICF in daily practice (Stucki et al. 2002).

1.6 DEVELOPMENT OF ICF CORE SETS

To facilitate the implementation of the ICF in daily and clinical practice, shorter versions of the ICF that include essential categories pertinent to a specific condition are warranted (Stucki et al. 2002). The ICF Core Sets (ICF-CS) can bridge this gap by aiding stakeholders in describing the most relevant areas of functioning (Selb et al. 2015b), using selected categories from the full ICF classification list. Each ICF-CS contains a comprehensive and a brief version. The Comprehensive ICF-CS provides an extensive description of an individual's functioning level, containing larger number of ICF categories which can be useful for intervention purposes, whereas the Brief ICF-CS can be used as a starting point for basic documentation of functioning and disability, applying fewer number of categories. The ICF-CS do not exclude the usage of the full ICF manual, rather it serves to facilitate the practical implementation of the ICF in daily practice. For this reason, users are allowed to add ICF categories that are missing in the ICF-CS to describe an individual's full functioning profile. The development of ICF-CS does not either imply a causal relationship between a health condition and impact. Instead, it aims to explore outcome in light of a health condition. Furthermore, the ICF-CS are intended to not only be used in clinical settings, but in any context where it is required to assess functioning, such as education, research and social settings. Users are free to derive assessment tools from the ICF-CS to describe and measure functioning across different contexts.

The development of ICF-CS can be divided into three separate phases (Selb et al. 2015b). Phase 1 represents the conductance of preparatory studies to collect evidence on health-related functioning. This phase follows four general principles as established by the ICF Research Branch in collaboration with the WHO. Firstly, the preparatory studies must adhere to a rigorous, scientific procedure that aim to describe functional health from various perspectives. Secondly, the studies must involve different types of stakeholder groups, meaning that the studies cannot only include experts or healthcare professionals, but also individuals living with a health condition and their caregivers. Thirdly, the participants must represent a broad range of professional disciplines to enrich the future application of the ICF-CS in multidisciplinary settings. Finally, each preparatory study must contain a cross-cultural sample, in line with WHO's goal of building a better, healthier future for people from all over the world. To ensure that these principles are followed, four preparatory studies involving a

comprehensive literature review (research perspective), an expert survey (expert perspective), a qualitative study (client and caregiver perspective) and a clinical study (clinical perspective) have been designed to collect evidence on health-related functioning. Once the preparatory studies are completed, phase 2 starts, which involves an international consensus conference where a group of international experts decide on which categories to include in the ICF-CS based on the empirical evidences. Phase 3 represents the implementation of the ICF-CS, with studies aiming to validate the ICF-CS. The implementation phase can take form in different ways and serve multiple purposes. To date, ICF-CS have been developed for neurological (e.g. multiple sclerosis), cardiovascular (e.g. stroke), musculoskeletal (e.g. rheumatoid arthritis) and psychiatric conditions (e.g. depression, bipolar disorder) (Ayuso-Mateos, Avila, Anaya, Cieza & Vieta, 2013; Cieza et al. 2004; Coenen et al. 2011; Geyh et al. 2004; Stucki et al. 2004). However, no ICF-CS have been developed for ADHD (Bölte et al. 2014a) and ASD (Bölte et al. 2014b).

1.7 SUMMARY AND CONCLUSIONS

The last century has witnessed major advances in medical treatment along with improved living standards that have enabled opportunities for individuals with disabilities to not only survive for a longer period of time, but also engage in different activities to fulfill individual aspirations and goals. This development has prompted the WHO to conceptualize health from a wider perspective, extending beyond descriptions of fatality and morbidity to include other vital dimensions such as health-related functioning and QoL.

ADHD and ASD are two common neurodevelopmental conditions with early-onset symptoms that tend to persist into adulthood, significantly disrupting everyday life functioning. The impact on functioning has been shown to reduce QoL and increase the risk for secondary problems (e.g. depression, anxiety, social isolation). Nevertheless, outcome in ADHD and ASD can vary substantially from one individual to another depending on multiple factors that extend beyond having a diagnosis. Hence, diagnosis alone is insufficient to understand health outcome in individuals with ADHD and ASD. Despite this realization, a majority of tools used in the clinical assessment of ADHD and ASD still focus on establishing a diagnosis rather than provide meaningful information on individual functioning. Indeed, current assessment tools may include information on certain functioning aspects, but these are usually not documented in the final coding of the measurement, as they may go beyond the boundaries defined by formal diagnostic criteria. Another gap concerns the lack of tools that are grounded in a biopsychosocial framework. For example, there are many tools that assess individual traits in ADHD and ASD, but very few explore environmental influences, which is surprising given their impact on individual development and outcome.

In 2001, the ICF was launched by the WHO, providing users a biopsychosocial classification system which describes functioning and disability from an etiological neutral perspective. Although the framework has been endorsed in clinical, education and social settings, the implementation of the ICF has nevertheless been a challenge given its comprehensive coding

scheme. For this reason, the development of ICF-CS was initiated to facilitate the implementation of the ICF in daily practice. The development consists of three phases, starting with the preparatory phase, which involves conducting four cross-cultural studies to investigate functional health from different stakeholder perspectives. To date, no ICF-CS have been developed for ADHD and ASD.

2 AIMS AND RATIONALE

This thesis is part of the overarching aim to develop standardized ICF-CS for ADHD and ASD to facilitate assessment of functioning and disability in ADHD and ASD from a biopsychosocial perspective. The tools will serve to i) support individualized assessment of functioning in ADHD and ASD, ii) increase environmental awareness of facilitators and barriers to functioning, iii) personalize interventions to target individual profiles of functional limitations and strengths, iv) create programs that target the environment to enhance functioning outcome, v) optimize allocation of resources based on individual profiles of functioning, and vi) improve communication and collaboration within (e.g. healthcare professionals) and between different stakeholder groups (e.g. professionals-clients, professionals-parents).

This thesis includes two of the four preparatory studies included in phase 1 of the development procedure of ICF-CS. Although the study objectives and methodologies were similar, the studies were conducted separately for ADHD and ASD, resulting in four scientific papers.

2.1 STUDY I AND II

Study I and II consisted of a mixed qualitative-quantitative study design, involving focus group discussions and semi-structured interviews with clients with ADHD and ASD, family members and professionals. The studies aimed to explore relevant areas of functioning and disability in ADHD and ASD as perceived by the client and social environment perspective using the ICF framework.

2.2 STUDY III AND IV

The objective of **study III and IV** was to investigate the clinical perspective of ADHD and ASD by applying a cross-sectional, multicenter design which involved international clinical researchers rating the functioning level of children, adolescents and adults with ADHD and ASD using a checklist with categories from the ICF.

3 METHODS

3.1 GENERAL CONSIDERATIONS

As discussed in the introduction part, the development of ICF-CS adheres to general principles that have been established by the ICF Research Branch and the WHO (Selb et al. 2015b). A study protocol was therefore provided with information on study design, procedure, material and data analysis. The aim of the protocol was to ensure that the preparatory studies followed a rigorous and scientific procedure, as these would subsequently provide the empirical basis for the expert decision-making in the international consensus conference, where the first version of ICF-CS for ADHD and ASD would be developed. Educational courses were arranged by the ICF Research Branch with training material and exercises that facilitated the researchers to become acquainted with the ICF and its use. To meet the demand of including cross-cultural and interdisciplinary study samples, the principal investigator of the project (Sven Bölte) organized an international Steering Committee (SC) with key opinion leaders in the field of ADHD and ASD who were tasked with supervising the project, recruiting participants, providing intellectual feedback and disseminating the study findings internationally. The SC members consisted of caregivers, clinicians, educators, researchers and self-advocates across all six WHO-regions (Africa, Eastern Mediterranean, Europe, South East Asia, The Americas & Western Pacific). Given that the preparatory studies were designed in a way to ensure that data was collected from as many international, professional and stakeholder groups as possible, the primary aim was not to compare groups (e.g. gender, age), but rather to ensure that the voices of the different stakeholders were taken into account. While each study contained a frequency analysis to show which areas of functioning and disability that were more or less recurring, these were only meant to facilitate the voting process in the international consensus conference.

Although the study protocol resolved many issues related to the preparatory studies, some were not addressed. One example is the issue of comorbidity and how to handle its impact on functioning in individuals with ADHD and ASD. Comorbidity is a common phenomenon in ADHD and ASD, which is why it is important that these are distinguished from the functional limitations and challenges that are caused by ADHD and ASD. Therefore, the research team was instructed to ensure that the discussions and ratings that took place during the preparatory studies focused on ADHD and ASD. Regarding individuals with comorbid ADHD and ASD diagnosis, they were asked to choose which study they wanted to participate in based on the diagnosis they felt impacted them the most. The level of information that would be presented in the study papers was also discussed by the SC members. While it was agreed that the data analysis should capture the ICF category that best described a specific functioning aspect, it was determined that these would be aggregated to second-level ICF categories when presenting the study findings. The reason for this decision was to ensure that the study findings would not be deemed too general or specific to be useful for practitioners and researchers.

3.2 ETHICAL CONSIDERATIONS

All studies were approved by the Regional Ethics Review Board in Stockholm and by the Local Ethics Review Boards at each of the participating study sites. Informed written and oral consent was collected from all participants prior to study participation. Each participant was informed that participation was voluntary and that they could withdraw their consent at any given time without any consequences. Participants were assured that personal data would only be available to authorized researchers and that no information would be shared for purposes other than research. The researchers also ensured the participants that their involvement would be anonymous and that the study findings would not be traced back to them.

A substantial number of participants were children and adolescents with neurodevelopmental impairments, which raised several questions about understanding risks and benefits with study participation. Although none of the studies included any invasive procedure (e.g. testing a new medication), the researchers were carefully instructed to put extra efforts into explaining study purpose and participation to children and adolescents. Participants who felt uncomfortable to take part in focus groups (study I and II) or face-to-face interviews (study III and IV) were offered alternative forms to participate (e.g. telephone interviews). In few cases, participants wished to have a parent present by their side to help them with answering questions, which they were allowed to do so. The moderators were instructed to be mindful of the participants' needs and ask for their feedback after focus group/interview conductance. Our experiences indicated that many children and adolescents found it interesting to discuss certain topics related to their own everyday life. It provided them with opportunities to highlight certain barriers and facilitators in the environment as well as discuss their own interest, abilities and skill sets. Although some questions were a bit challenging and difficult to answer (e.g. body functions, personal factors), others (e.g. environmental factors, individual strengths) were not and the information could in the future be valuable to future implementation of assessment tools that capture functioning in individuals with ADHD and ASD.

Since the studies focused on capturing relevant aspects of everyday life functioning in individuals with ADHD and ASD, many adults with diagnosis as well as parents and professionals found the discussion questions and clinical ratings to be important. Specifically, they found the biopsychosocial perspective on functional health to be refreshing and exhaustive. Indeed, many stakeholders, especially adults with ADHD and ASD, mentioned the inclusion of environmental and personal factors to be complementary to questions capturing impairments in body functions and body structures. The inclusion of strength-based ratings and questions was also positively received by many participants, concurring that a balanced approach towards individual assessment of ADHD and ASD is the right way to go. When presenting the ICF to study participants, common misconceptions were addressed. For example, the ICF does not categorize individuals into different entities, but rather classifies information on functioning and disability to facilitate intervention planning and systematic coding of health-related information (WHO, 2001, 2007). It was important that the

moderators and clinical investigators were able to explain the ICF to avoid any potential misunderstandings. Hence, all moderators and investigators were introduced to the ICF and its rationale prior to study conductance.

3.3 DESIGN AND PROCEDURE

3.3.1 Study I and II

To capture the perspectives of diagnosed individuals and their social environment on functional health in ADHD and ASD, a mixed qualitative-quantitative study methodology was employed, involving focus group discussions and individual semi-structured interviews with diagnosed individuals, family members and professionals. To ensure that different stakeholder groups and countries were involved, participants were divided into different groups based on age (i.e. childhood, adolescence, adulthood), perspective (i.e. diagnosed individuals, family members, professionals) and WHO-region (i.e. Africa, Eastern Mediterranean, Europe, South East Asia, The Americas). Table 1 and 2[1] list the different groups that were included in the final analysis in ADHD and ASD. Study I (ADHD) generated 16 stakeholder groups (n = 76 participants), of which 10 were conducted with focus groups (n = 48 participants) and 6 with semi-structured interviews (n = 28 participants). All participants consented (both written and orally) to have their focus group discussions and individual interviews audio-recorded, except for the parent group in India (no audio recording was made here). Study II (ASD) yielded 19 stakeholder groups, of which 6 were groups that involved semi-structured interviews (n = 26 participants). The remaining 13 stakeholder groups employed focus group discussions (n = 64 participants). All participants gave their written and oral consent to have the sessions audio-recorded. Previous qualitative studies of ICF-CS development reached data saturation after six focus groups (Coenen, Basedow-Rajwich, Konig, Kesselring & Cieza, 2011; Granberg et al. 2014; Gradinger et al. 2011), which is substantially lower than the number of focus groups that were included in study I and II. The reason for this difference could be that previous qualitative studies involved fewer stakeholder groups from fewer number of countries.

Focus groups were chosen as data collection method because it enables participants to discuss certain topics with one another and produce insights that can lead to rich variety of information (Flick, 2014). The sample size of focus groups is mostly determined by the topic that is being discussed as well as the participant groups that are involved in the discussions. Usually, it is recommended that focus groups include six to ten participants, but given that we anticipated potential ADHD (e.g. impulsivity, hyperactivity) and ASD-related difficulties (e.g. social communication) to interfere with focus group conductance, smaller size of participants from four to eight participants was deemed more convenient in order to ensure high-quality interaction between participants. As part of the data collection method, individual semi-structured interviews were conducted in both studies to comply with

[1] All tables in this thesis are derived from the published articles with the exception of Table 11, 12 and 13.

individual wishes to participate in a more anonymous and intimate setting. Individual interviews were also employed to address logistical challenges, which often resulted in last-minute cancellation of scheduled focus groups. The focus groups varied in length from 35 to 120 min (including short breaks), whereas the individual interviews typically lasted from 15-115 min. Moderators with clinical and/or research background were appointed from each study site to lead the focus group discussions and individual interviews. Trustworthiness was established according to Lincoln and Guba (1985) using member checking, triangulation and reflexivity. Member checking was applied as part of the focus group conductance, with the moderators summarizing the discussions and checking with each participant that his or her accounts were accurately understood. Member checking also provided participants with opportunities to add or correct certain information that was missing. Similar technique was also used in the individual interviews. Triangulation involved using different informants (i.e. clients, family members, professionals) to investigate functioning and disability in ADHD and ASD, ensuring that no relevant parties are missing. Reflexivity consisted of having multiple investigators and researchers, representing different cultural and professional background, reviewing the transcripts and analyzing these to minimize potential risks for bias. Each focus group and individual interview was audio-recorded and transcribed verbatim. Non-English transcriptions were translated into English by approved translators, with the exception of Swedish transcriptions, which were directly analyzed by native speakers.

Table 1. Composition of stakeholder groups by country in study I (ADHD)

Country	WHO-region	Number of participants (%)	Data collection method
Brazil	**The Americas**	**17 (22%)**	**Focus groups**
Children		5 (29%)	Focus group
Adolescents		5 (29%)	Focus group
Adults		7 (42%)	Focus group
India	**South East Asia**	**5 (7%)**	**Semi-structured interviews**
Parents		5	Semi-structured interviews
Saudi Arabia	**Eastern Mediterranean**	**12 (15%)**	**Focus groups**
Adults		4 (33%)	Focus group
Parents		4 (33%)	Focus group
Health prof.		4 (33%)	Focus group
South Africa	**Africa**	**5 (7%)**	**Focus groups**
Child/Adolesc.		5	Focus group
Sweden	**Europe**	**37 (49%)**	**Both**
Children		5 (14%)	Semi-structured interviews
Adolescents		5 (14%)	Semi-structured interviews
Adults		5 (14%)	Focus group
Parents to children		5 (14%)	Semi-structured interviews
Parents to adolesc.		4 (11%)	Semi-structured interviews
Interest org. members		4 (11%)	Focus group
School personnel		5 (14%)	Focus group
Other professionals		4 (11%)	Semi-structured interviews

Table 2. Composition of stakeholder groups by country in study II (ASD)

Country	WHO-region	Number of participants (%)	Data collection method
Canada	**The Americas**	**14 (16%)**	**Both**
Adults*		1 (7%)	Semi-structured interview
Professionals		4 (29%)	Focus group
Family members		9 (64%)	Focus group
India	**South East Asia**	**21 (23%)**	**Focus groups**
Adults		4 (19%)	Focus group
Parents		5 (23%)	Focus group
Trainee parents		6 (29%)	Focus group
School personnel		6 (29%)	Focus group
Saudi Arabia	**Eastern Mediterranean**	**10 (11%)**	**Focus groups**
Parents		6 (60%)	Focus group
Health prof.		4 (40%)	Focus group
South Africa	**Africa**	**12 (13%)**	**Focus groups**
Adults		2 (17%)	Focus group
Family members		6 (50%)	Focus group
Family/Teachers		4 (33%)	Focus group
Sweden	**Europe**	**33 (37%)**	**Both**
Children		4 (12%)	Semi-structured interviews
Adolescents		4 (12%)	Semi-structured interviews
Adults		4 (12%)	Semi-structured interviews
Parents to children		5 (16%)	Semi-structured interviews
Parents to adolesc.		4 (12%)	Focus group
Interest org. members		4 (12%)	Focus group
School personnel		4 (12%)	Semi-structured interviews
Other professionals		4 (12%)	Semi-structured interviews

*Since only one adult was included from Canada, this adult was grouped into the Swedish adult stakeholder group for the frequency analysis.

3.3.2 Study III and IV

To explore the clinical perspective on functional health in ADHD and ASD, an international cross-sectional study design, involving multi-centers across different WHO-regions, was employed for study III (ADHD) and IV (ASD). List of participating countries and WHO-regions can be found in Table III and IV. As recommended by the ICF Research Branch, study III and IV contained broad representation of countries and WHO-regions. Participating sites were specialized in NDD, including ADHD and ASD. Clinical researchers rated the functioning level of children, adolescents and adults with ADHD and ASD using a checklist comprising shortlist of second-level categories from the ICF. The clinical investigators were instructed to rate the functioning level of participants based on information from available sources. These included medical records, medical history, questionnaires (e.g. ADI-R, BRIEF, Conners-3, VABS), psychometric test scores (e.g. WISC, WAIS), observation schedules (e.g. ADOS-2), clinical observations and interviews with the participant and/or caregivers. The latter could vary depending on age of the participant and his or her developmental level. In cases where the different information sources generated data that was

discordant, the clinical investigators were told to rely on clinical judgment. Prior to the interviews, the clinical investigators checked available medical information to extract data on socio-demographic variables, comorbidity and ADHD and ASD-related functioning aspects. Interviews with participants and/or caregivers were then conducted to rate the remaining ICF-categories in the checklist. The length of the interviews varied from 25 to 120 min. Owing to logistical challenges, telephone interviews were occasionally used as alternative to face-to-face interviews.

Table 3. Participants by country and WHO-region in study III (ADHD)

Country	WHO-region	N (%)
Sweden	Europe	48 (43)
Taiwan	Western Pacific	24 (21)
Germany (Dresden + Marburg)	Europe	14 (13)
Saudi Arabia	Eastern Mediterranean	9 (8)
Italy	Europe	6 (5)
Portugal	Europe	6 (5)
India	South East Asia	4 (4)
Denmark	Europe	1 (1)

Table 4. Participants by country and WHO-region in study IV (ASD)

Country	WHO-region	N (%)
Sweden	Europe	33 (27)
Germany (Dresden + Marburg)	Europe	26 (21)
Brazil	The Americas	15 (12)
Denmark	Europe	12 (10)
Saudi Arabia	Eastern Mediterranean	11 (9)
Greece	Europe	6 (5)
Italy	Europe	6 (5)
Japan	Western Pacific	6 (5)
Portugal	Europe	6 (5)
Argentina	The Americas	1 (1)

3.4 PARTICIPANTS

3.4.1 Study I and II

Participants were recruited between February and December 2015. Study participation involved meeting certain criteria. Firstly, participants had to have a primary clinical diagnosis of ADHD (combined or predominant inattentive or hyperactive-impulsive presentation) or ASD (or ASD subtype) according to the diagnostic criteria of the ICD-10, DSM-IV/TR or DSM-5. Exception was made in cases where non-diagnosed individuals received treatment for ADHD or ASD. Secondly, participants had to be an immediate family member or professional caregiver, or other closely involved person in the everyday life of individuals with ADHD or ASD. Thirdly, for data collection purposes, participants had to be proficient in the language of the country where the focus group or interview took place. Participants younger than 7 years of age were excluded from the study. To capture a diverse perspective

on functional health in ADHD and ASD, purposive sampling, involving maximum variation sampling, was applied to ensure that participants with different characteristics were included in the studies (Flick, 2014). Characteristics of importance included age, gender, ADHD and ASD presentation/subtype, stakeholder perspective (i.e. clients, family, professionals), WHO-region (i.e. country) and professional background (i.e. caregivers, clinicians, educators). Each study site had a clinical research team who was responsible for recruiting participants. National and local interest organizations for ADHD and ASD were approached to disseminate information about the studies, facilitating the recruitment procedure. The contributions of stakeholder groups were made by the project SC members.

In **study I**, 82 participants met the inclusion criteria for study participation, of which 76 completed the focus groups or semi-structured interviews. Attrition was related to not showing up for scheduled focus groups (n = 2) or regretting to participate in the study (n = 1). Moreover, three children with ADHD were initially scheduled to be included in the study, but given their high level of restlessness, it was deemed that they could not take part in focus groups or individual interviews. A summary of the participants' group membership, age and gender can be found in Table 5. Table 6 describes the sociodemographic background of diagnosed individuals with ADHD. Most family members were related to children with ADHD (n = 9), followed by adolescents (n = 8) and adults (n = 1). The family members also mentioned their loved ones to be diagnosed with ADHD combined (n = 12), inattentive (n = 5) and hyperactive-impulsive presentation (n = 1). The interest organization members stated that they knew individuals across the entire ADHD spectrum.

Study II consisted of 102 eligible participants, of which 90 took part in the focus groups or semi-structured interviews. Some participants did not show up for the study (n = 8) or chose to decline participation (n = 4) after initial consent. Table 7 shows the participants that were included in the final analysis with regards to stakeholder group, gender and age. Table 8 represents data on sociodemographic background of diagnosed individuals. The most common ASD subtype among diagnosed individuals was Asperger's syndrome (n = 11), followed by classic autism/autistic disorder (n = 2) and atypical autism/PDD-NOS (n = 2). Four participants did not report ASD subtype. An overwhelming majority of the immediate family members specified their relative to be diagnosed with classic autism/autistic disorder (n = 19) or Asperger's syndrome (n = 17). Only five family members mentioned their relative to have atypical autism/PDD-NOS. Two did not respond to the question. There was a substantial variation in the age group of the relatives with ASD. Thirteen family members mentioned to be related to adults with ASD, twelve to young school-aged children, eleven to preschool children and six to adolescents. Regarding the professional group, most (n = 20) reported working with diagnosed individuals across the entire lifespan. Only few mentioned to work exclusively with children (n = 3), preschool children (n = 2), adults (n = 2) or adolescents (n = 1). The experiences of the professionals were mostly based on autistic individuals across the entire spectrum.

Table 5. Information on stakeholder group, gender and age in study I (ADHD)

Stakeholder groups	Size of group N (%)	Gender (male) N (%)	Age M (SD) Range
Clients	**41 (54)**	**25 (61)**	**21 (12.9) 7-61**
Children	13 (32)	9 (69)	10 (1.6) 7-12
Adolescents	12 (29)	8 (67)	15 (1.3) 13-17
Adults	16 (39)	8 (50)	35 (10.1) 24-61
Immediate family members	**22 (29)**	**4 (18)**	**45 (8.9) 31-58**
Parents	18 (82)	4 (22)	46 (9.2) 31-58
Interest org. members*	4 (18)	0	40 (5.7) 35-47
Professionals	**13 (17)**	**4 (31)**	**42 (9.8) 30-59**
School personnel**	5 (38)	1 (20)	49 (8.4) 40-59
Other professionals***	8 (62)	3 (37)	36 (6.4) 30-47

*Interest organization members represented individuals with family relatives diagnosed with ADHD. The members aim to increase public awareness about ADHD and provide support to diagnosed individuals and their relatives.

**School personnel included teachers, special educators and principals.

***Other professionals consisted of healthcare professionals (e.g. psychiatrists, psychologists, etc.) and professionals who work closely with individuals with ADHD in daily life, such as personal assistants and residential caregivers

Table 6. Sociodemographic background of diagnosed individuals in study I (ADHD)

	Children 7-12 years N (%)	Adolescents 13-17 years N (%)	Adults ≥18 years N (%)
ADHD presentation/subtype			
ADHD, combined	4 (31)	2 (17)	11 (69)
ADHD, inattentive	4 (31)	4 (33)	4 (25)
ADHD, hyperactive-impulsive	3 (23)	4 (33)	1 (6)
ADHD, unspecified	2 (15)		
Did not report		2 (17)	
Comorbidity			
Yes*	1 (8)	1 (8)	7 (44)
No	12 (92)	11 (92)	9 (56)
Treatment			
Medication	6 (46)	5 (42)	5 (31)
Psychosocial intervention		1 (8)	1 (7)
Combined medication and psychosocial intervention	4 (31)	3 (25)	5 (31)
No treatment	3 (23)		5 (31)
Did not report		3 (25)	
Education background			
Primary/high school	13 (100)	11 (92)	2 (13)
University/college			13 (81)
Vocational education			1 (6)
Did not report		1 (8)	
Living situation			
Living with parents	10 (77)	11 (92)	8 (50)
Living with a partner			3 (19)
Living independently			3 (19)
Other living situation**	2 (15)		2 (12)
Did not report	1 (8)	1 (8)	
Work status			
Students	13 (100)	11 (92)	1 (5)
Full time employment			6 (38)
Part time employment			2 (13)
Self-employment			2 (13)
Volunteer work			2 (13)
Combined forms of employment***			2 (13)
Sick leave			1 (5)
Did not report		1 (8)	

*Comorbidities included dyslexia, dysgraphia, dyscalculia, ASD, social phobia, Tourette's syndrome, obsessive compulsive disorder, among others.

**Living in a communal setting, living separate from a partner or living with extended family members.

***Self-employed and doing volunteer work

Table 7. Information on stakeholder group, gender and age in study II (ASD)

Stakeholder groups	Size of group N (%)	Gender (male) N (%)	Age M (SD) Range
Clients	**19 (21)**	**11 (58)**	**25 (16.2) 9-67**
Children	4 (21)	2 (50)	11 (1.5) 9-12
Adolescents	4 (21)	4 (100)	16 (1.8) 14-17
Adults	11 (58)	5 (45)	34 (16.2) 18-67
Immediate family members*	**43 (48)**	**4 (9)**	**43 (10.6) 22-68**
Parents/grandparents	37 (86)	4 (11)	45 (10.2) 23-68
Trainee parents	6 (14)	0	32 (5.3) 22-37
Professionals	**28 (31)**	**6 (21)**	**43 (12.9) 23-73**
Interest. org. members**	4 (14)	1 (25)	50 (11.6) 34-62
School personnel***	12 (43)	2 (17)	43 (13.9) 23-73
Other professionals****	12 (43)	3 (25)	40 (12.0) 24-59

*Immediate family members group included individuals with relatives diagnosed with ASD. Some of these members were training to become professionals in ASD.

**Interest organization members represented individuals who had family relatives with ASD or who worked closely with diagnosed individuals and their family members. The members aim to increase public awareness about ASD and provide support to diagnosed individuals and their relatives.

***School personnel consisted of principals, teachers and special educators.

****Other professionals varied from healthcare professionals (e.g. psychiatrists, psychologists, nurses) to individuals who worked closely with individuals with ASD, such as personal assistants and residential caregivers.

Table 8. Sociodemographic background of diagnosed individuals in study II (ASD)

	Children 9-12 years N (%)	Adolescents 13-17 years N (%)	Adults ≥18 years N (%)
ASD subtype			
Asperger syndrome	2 (50)	2 (50)	7 (64)
Classic autism/autistic disorder	1 (25)	1 (25)	
Atypical autism	1 (25)	1 (25)	
Did not report			4 (36)
Comorbidity			
Yes*	4 (100)	2 (50)	5 (45)
No	0	2 (50)	6 (55)
Treatment			
Yes**	2 (50)	2 (50)	4 (36)
No	2 (50)	2 (50)	7 (64)
Education background			
Primary/high school	4 (100)	4 (100)	2 (18)
University/college			5 (46)
Vocational education			2 (18)
Did not report			2 (18)
Living situation			
Living with parents	4 (100)	3 (75)	5 (46)
Living with a partner			4 (36)
Living independently			2 (18)
Other unspecified living situation		1 (25)	
Work status			
Students	4 (100)	4 (100)	3 (27)
Full time employment			1 (9)
Self-employment			1 (9)
Supported employment			3 (27)
Retired/volunteer work			1 (9)
Did not report			2 (19)

*Comorbidities ranged from mood and anxiety disorders (e.g. depression, generalized anxiety disorder, obsessive compulsive disorder) to other NDD (e.g. Tourette syndrome, developmental coordination disorder, ADHD)

**Treatments that were received included medication and psychosocial treatment (e.g. social skills training)

3.4.2 Study III and IV

Recruitment of participants in study III (ADHD) and IV (ASD) took place between March and August 2016. Participants had to meet the inclusion criteria of having a primary clinical diagnosis of ADHD or ASD according to the ICD-10, DSM-IV/TR or DSM-5. Similar to study I and II, non-diagnosed individuals who received treatment for ADHD or ASD were also included in the studies. Caregivers or diagnosed individuals who could not communicate in the native language of the country they resided in were excluded from the

study. International study sites were contacted to contribute with clinical cases of ADHD and ASD. Some cases were provided by the project SC members, while others were contributed by clinical researchers who expressed interest in becoming involved with the ICF-CS development. Each study site had a team of clinical researchers who were in charge of recruiting participants. Local and national interest organizations for ADHD and ASD also assisted with the recruitment process, specifically recruiting adults with ADHD and ASD. Some preschoolers with ASD were also recruited via interest organizations. In most adult cases, access to medical records was limited, which is why the rating of functioning level primarily relied on information from interviews. In line with other clinical studies for ICF-CS development (Finger et al. 2011; Schiariti & Mâsse, 2014), we aimed to enroll at least 100 participants per diagnosis.

In **study III**, 119 participants consented (both written and orally) to participate, of which 112 completed the study. Attrition included not showing up for assessment (n = 4), or withdrawing participation after initial consent (n = 3). The sociodemographic background of the participants can be found in Table 9. Most participants had a diagnosis of combined ADHD (n = 76, 68 %). Fewer cases involved predominant inattentive (n = 25, 22 %) and hyperactive-impulsive symptom presentation (n = 4, 4 %). One participant was diagnosed with unspecified ADHD (1 %), while six (5 %) did not have their ADHD symptom presentation specified. Comorbidity was reported in the majority of the cases (n = 62, 55 %), which included other NDD (e.g. ASD, motor tics, communication disorders; n = 25, 22 %), mood and anxiety disorders (e.g. depression, anxiety, obsessive compulsive disorder, bipolar disorder; n = 17, 15 %), externalizing behavior problems (e.g. conduct disorder, oppositional defiant disorder; n = 10, 9 %) and learning disorders (e.g. dyslexia, dysgraphia, dyscalculia; n = 7, 6 %).

In **study IV**, 126 participants met the inclusion criteria of the study and consented (both written and orally) to participate in the clinical assessment. Of the 126 participants, 122 were included in the final analysis, with three participants not showing up for assessment and one declining study participation after initial consent. Table 10 summarizes the sociodemographic background of the participants included in the final analysis. Asperger's syndrome was featured in forty individuals (33 %), followed by twenty-six cases of classic autism/autistic disorder (21 %) and eleven with atypical autism/pervasive developmental disorder not otherwise specified (9 %). Forty-five participants (40 %) were diagnosed with Autism Spectrum Disorder as specified by the DSM-5 criteria. Most participants (n = 94, 77 %) had at least one additional diagnosis. Common diagnoses included ADHD (n = 28, 23 %), intellectual disability (n = 19, 16 %), depression (n = 10, 8 %), specific developmental disorder of motor function (n = 8, 7 %) and generalized anxiety disorder (n = 5, 4 %).

Table 9. Sociodemographic background of diagnosed individuals with ADHD (study III)

Sociodemographic variables	N (%)	Gender (male) N (%)	Age M (SD) Range
Age group			
Children with ADHD (age: 6-12 years)	51 (46)	44 (86)	9.0 (1.8) 6-12
Adolescents with ADHD (age: 13-17 years)	17 (15)	13 (76)	14.3 (1.6) 13-17
Adults with ADHD (age: ≥18 years)	44 (39)	15 (34)	37.3 (11.7) 18-61
Marital status			
Single	82 (73)		
Married	13 (12)		
In a domestic relationship	6 (5)		
Divorced/separated	3 (3)		
Other marital status*	8 (7)		
Education level			
Primary/high school	80 (71)		
University/college	23 (21)		
Vocational education	3 (3)		
Other education level**	6 (5)		
Work status			
Student	67 (59)		
Full time employment	19 (16)		
Combined forms of employment	9 (8)		
Receiving benefit grants	4 (4)		
Part time employment	3 (3)		
Sick leave	3 (3)		
Unemployment	3 (3)		
Self-employment	2 (2)		
Sickness benefits	1 (1)		
Volunteer work	1 (1)		
Living situation			
Living with parents	65 (59)		
Living with a partner	19 (16)		
Living independently	18 (16)		
Other living situation***	10 (9)		

*Other marital status includes dating, long-distance relationships, live-apart, etc.

**Other education level includes preschool and folk high school.

***Other living situation includes living with a friend or grandparent, residential care, etc.

Table 10. Sociodemographic background of diagnosed individuals with ASD (study IV)

Sociodemographic variables	N (%)	Gender (male) N (%)	Age M (SD) Age range
Age group			
Children with ASD (age: 4-12)	46 (38)	36 (78)	8.3 (2.4) 4-12
Adolescents with ASD (age: 13-17)	39 (32)	33 (85)	15.1 (1.5) 13-17
Adults with ASD (age: ≥18 years)	37 (30)	21 (57)	33.1 (10.7) 18-55
Marital status			
Single	112 (92)		
Divorced/separated	4 (4)		
Married	3 (2)		
Other marital status*	3 (2)		
Education level			
Primary/high school	81 (66)		
Vocational education	13 (11)		
University/college	10 (8)		
Other education level**	17 (14)		
Missing data	1 (1)		
Work status			
Student	80 (65)		
Supported employment	6 (5)		
Part time employment	2 (2)		
Sickness benefits	2 (2)		
Unemployment	2 (2)		
Combined forms of employment	15 (12)		
Other work status***	15 (12)		
Living situation			
Living with parents	98 (81)		
Living independently	16 (13)		
Living with partner	3 (2)		
Combined living situations	1 (1)		
Other living situation****	4 (3)		

*Other marital status involves dating, live-apart.

**Other education level involves daycare, preschool and folk high school.

***Other work status involves daily activities, wage-subsidized employment, etc.

****Other living situations involves residential care living, living with a friend, etc.

3.5 MATERIAL

3.5.1 Study I and II

An interview guide (Appendix 1 and 2) consisting of six questions that covered all components of the ICF (i.e. body functions, body structures, activities and participation,

environmental factors and personal factors) was employed for the focus group discussions and semi-structured interviews in study I (ADHD) and II (ASD). The six questions followed the ICF-CS preparatory study protocol that was developed by the WHO and ICF Research Branch. Given that previous research studies indicate certain individual skill sets to be associated with ADHD and ASD (Hupfeld et al. 2018; Nilsson-Jobs et al. 2018; Remington & Fairie, 2017), an additional question inquiring about individual strengths was added in the interview guide by the research team. In addition to the questions, the interview guide also contained information on what the moderators could do to stimulate discussion and clarify the responses of the participants. For younger participants with ADHD and ASD, certain adaptations were made in the interview guide. For example, the order of the questions was changed to start with easier questions related to activities and participation, environmental factors and individual strengths. Questions that captured personal factors, body functions and body structures were discussed later and the moderators were instructed to use non-verbal communication methods to further communicate the intent of the questions. Examples of non-verbal communication methods included hand-gestures (e.g. pointing to the heart or the brain) or using papers to draw. In addition, some of the focus groups and individual interviews were arranged in rooms with whiteboards, which the participants could use to communicate feelings or thoughts about a certain topic. Throughout the focus group discussions and individual interviews, the moderators were instructed to be mindful about asking leading questions that might prompt the participants to respond in a desirable manner. The aim of the studies was to capture the views of the participants and not the moderators, which is why each focus group discussion and individual interview had a second person in attendance who took notes and provided feedback to the moderator. This person was also in charge of ensuring that the audio-recording devices were functioning properly. Each participant received a case record form (CRF) with questions related to their own sociodemographic background, which they were asked to complete and return before or after the focus group discussions and individual interviews concluded. Transcriptions from focus group discussions and individual interviews were analyzed in Microsoft Excel.

3.5.2 Study III and IV

The ICF Checklist 2.1a is a rating tool that records information on functioning and environment based on shortlist of 123 second-level categories derived from the ICF (WHO, 2003). These include 48 activities and participation categories, 32 environmental factors, 31 body functions and 12 body structures. The assessment of these categories is usually done by ICF qualifiers, which utilizes a five-point scale that defines severity of functioning impairments and limitations according to how often a specific problem is present in an individual's life. The validity and feasibility of the checklist has previously been demonstrated in patients with chronic and mood conditions (e.g. diabetes mellitus, osteoarthritis, ischemic heart disease, depression) (Ewert et al. 2004; Okochi, Utsunomiya & Takahashi, 2005). For study III (ADHD) and IV (ASD), a modified version of the ICF

Checklist 2.1a was used[2] (an excerpt from the checklist can be found in Appendix 3 and 4). The modification involved making the checklist content more specific to ADHD and ASD. This was done by reviewing findings from our previous three preparatory studies (literature review, expert survey, qualitative study) to check if there were candidate categories for ADHD and ASD that were not represented in the checklist. The checklist content for ADHD increased from 123 to 153 second-level categories. Of the 30 second-level ICF categories that were added in the checklist, 14 were activities and participation, 12 were body functions and 4 were environmental factors. The 153 second-level ICF categories were distributed across all components of the ICF; 62 activities and participation, 43 body functions, 36 environmental factors and 12 body structures. Regarding the ASD study, 38 second-level ICF categories were added in the checklist, representing 17 activities and participation, 17 body functions, 3 environmental factors and 1 body structure. The final version comprised 161 second-level ICF categories; 65 activities and participation, 48 body functions, 35 environmental factors and 13 body structures. Another modification that was done to the checklists was the introduction of strength-based ratings, which allowed clinical investigators to not only rate functional limitations and impairments, but also certain abilities and skill sets that individuals with ADHD or ASD mastered or were better at compared to the average population.

The checklist for ADHD and ASD was divided into four parts. Part 1 comprised the inclusion criteria of the study. Part 2 elicited information on participants' sociodemographic background (e.g. age, diagnosis, gender, marital status, education level, etc.). Part 3 included ratings of second-level ICF categories. Part 4 investigated personal factors that were deemed relevant to ADHD or ASD. The ICF categories were rated according to an adapted version of the numeric rating scale (NRS). The NRS has previously been validated and applied in assessments related to pain intensity (Ferreira-Valente, Pais-Ribeiro & Jensen, 2011). The NRS is composed of an eleven-point scale, with 0 representing "no", 1-3 "mild", 4-6 "moderate" and 7-10 "severe" symptoms/impairment (McCaffery & Beebe, 1989). Same metrics was used to assess individual strengths. The main reason for applying the NRS was because of its simplicity and ease of administration and scoring. Unlike the ICF qualifiers, which define severity of functioning impact according to how often a specific problem is experienced in daily life, the NRS does not offer a restrictive definition, hence enabling users to assess other factors that may be important to individual functioning, such as degree and duration of impairment/limitation. Another reason for using the NRS was that previous studies have shown the ICF qualifiers to be a bit difficult to interpret and implement by different stakeholders in clinical settings (Dalen, Nyquist, Saebu, Roe & Bautz-Holter, 2013; Ibramigova, Granlund & Björck-Åkesson, 2009). NRS was also used to assess environmental factors, with 0 indicating "no barrier or facilitator", +10 "complete facilitator" and -10 "complete barrier". For all the categories in the ICF checklists, scoring options of "Not applicable" and "Not specified" were available. The former was used in cases when an ICF

[2] The electronic version of the thesis includes the full version of the checklists.

category was not appropriate to use to describe a certain individual (e.g. asking a young child about university studies), whereas the latter was used when there was insufficient information to rate a specific ICF category. Aspects of functioning and environment that were deemed relevant to ADHD and ASD, but not included in the checklists, were documented and rated according to the NRS. Information sources that were used to rate the ICF categories included clinical observations, medical records, psychological test results and interviews with participant and/or caregivers. To minimize the risk of over or underestimation of individual strengths and difficulties during interviews, the clinical investigators were instructed to ask participants for clarifications and examples that could facilitate the rating. Once the ICF ratings were concluded, the clinical investigators had an empty page at their disposal to document any personal factors that either hindered or facilitated individuals' everyday life functioning. Personal factors were not rated, but documented descriptively during interviews with participants and/or caregivers.

Considerations were made to ensure quality assurance. For example, the clinical investigators were required to participate in a web-based ICF self-learning course (http://icf.ideaday.de/). The main rationale was to get the investigators more acquainted with the ICF model and coding scheme. Once the investigators completed the course, they received examples of questions which they could use for the interviews with participants and/or caregivers. Certain modifications were made in the checklist content to facilitate the rating of ICF categories. For example, each second-level ICF category was provided with clear descriptions and inclusion criteria that made it easier for the investigators to rate them. Skype meetings were arranged with investigators who expressed a further need to discuss certain ICF categories. The checklists were translated into the languages of the different study sites, with the exception of the Danish study site, which used an English version. The coordinator provided each study site with additional material that facilitated the study procedure, e.g. sending interview experiences from other study sites.

3.6 DATA ANALYSIS

3.6.1 Study I and II

A deductive qualitative content analysis (Krippendorff, 2013) was employed in study I (ADHD) and II (ASD) to examine verbatim transcriptions from focus group discussions and individual semi-structured interviews. The analysis followed the procedure of meaning condensation (Kvale, 1996), which entails a couple of steps. In the first step, the researchers sat down and read the transcriptions carefully to acquire a general overview of the collected data. In the second step, the researchers divided the transcripts into meaningful units. This procedure was done separately by the researchers. Each meaningful unit contained a specific chunk of text that was related to a common theme that was deemed important to our study purpose. As soon as a shift in meaning was detected in the text, a new meaningful unit was extracted. Hence, the meaning unit division does not follow linguistic grammatical rules

(Karlsson, 1995). Instead, the text is divided at the point where the researchers detect a shift in meaning. Once the meaningful units were extracted, the researchers proceeded to step three, where meaningful concepts were extracted from the units. Meaningful concepts refer here to concepts that capture the essence of participants' statements. These were subsequently linked to ICF categories according to set of rules and guidelines as established by the ICF Research Branch (Cieza et al. 2002; Cieza et al. 2005). The general consensus is that meaningful concepts should be linked to the most precise ICF category. For example, "difficulties with carrying out defecation appropriately" should not be linked to second-level ICF category "d530 Toileting", but rather to fourth-level category "d53011 Carrying out defecation appropriately", which is subordinate to d530 Toileting. Meaningful concepts may be linked to several ICF categories, as long as the different categories do not exclude each other. Important concepts that cannot be linked to the ICF coding scheme are assigned as personal factors (PF), health conditions (HC), nondefinable (ND) or not covered (NC). ND codes are usually used when the meaningful concept is too broad to be captured by the ICF coding scheme. NC codes are used in cases when the meaningful concept is not contained in the ICF framework. PF codes are used when the meaningful concept refers to inherent qualities of the individual that are not part of the condition (e.g. age, beliefs, interests, living situation, personality traits). HC codes are used when participants refer to certain diagnoses (e.g. GAD, OCD, CD, etc.). Strengths related to ADHD and ASD were also analyzed and linked to the ICF as mentioned above. An excerpt from the linking analysis be found in Table 11 for study I and II.

Transcriptions from focus group discussions and semi-structured interviews were analyzed by two independent researchers in order to ensure consistency of linking results. Given that study I and II involved study sites from different countries, at least one independent researcher was included from each study site (with the exception of India) to capture culture-specific expressions. In total, seven independent researchers were involved in the linking of focus groups and individual interviews in study I and II. Prior to the linking of actual data, each researcher received linking exercises and training material from the ICF Research Branch that prepared them for the subsequent analysis of focus groups and individual interviews. Once the researchers completed the linking analysis (which was done separately by the researchers), they met with one another to reach consensus on the categories that were chosen. In cases where no consensus could be reached, the coordinator from the ICF Research Branch made the final decision. However, this option was never used, as the researchers resolved their differences with one another. Inter-rater agreement was calculated using Cohen's Kappa. Table 12 and 13 show the results from the inter-rater agreement for study I and II.

A frequency analysis was conducted on the transcriptions from the different focus group discussions and semi-structured interviews. For ADHD and ASD-related strengths, only recurring concepts and categories were summarized. Concepts that were linked to third or fourth-level ICF categories were aggregated to second-level candidate categories. To avoid potential biases in responses (e.g. a participant mentioning a specific functioning aspect more

than once during an interview or focus group), an ICF category was only counted once for each stakeholder group that involved focus groups or semi-structured interviews. The maximum number of stakeholder groups in ADHD study was 16 (focus groups = 10; semi-structured interviews = 6). The corresponding number for ASD was 19 (focus groups = 13; semi-structured interviews = 6). In accordance with previous preparatory ICF-CS qualitative studies (Boonen, van Berkel, Cieza, Stucki & van der Heijde, 2009; Coenen et al. 2011), an ICF category that was identified in at least one stakeholder group was included as candidate category for ADHD and ASD, irrespective of data collection method.

Table 11. Examples of linking analysis for study I (ADHD) and II (ASD)

Transcript	Meaningful unit	Meaningful concept	R1	R2
"I use Ritalin to calm down. Before when I didn't take the medication, I would be agitated. But when I started taking it, I became calmer and learnt things that I didn't know before. I think it is boring to take the medication all the time. And my cousin tells me all the time that I am stupid and that I don't know how to read. I can read, but when he says that I get really annoyed".[1]	I use Ritalin to calm down. Before when I didn't take the medication, I would be agitated. But when I started taking it, I became calmer and learnt things that I didn't know before.	Ritalin (as a facilitatory factor)	e1101 Drugs	e1101 Drugs
	I think it is boring to take the medication all the time.	taking medication is boring	NC -taking medication is boring	PF -taking medication is boring
	And my cousin tells me all the time that I am stupid and that I don't know how to read. I get really annoyed when he says that.	negative attitude of the cousin	e415 Individual attitudes of extended family members	e415 Individual attitudes of extended family members
"Socially, children with ADHD are able to help others more than themselves and also try to fulfill the needs of their family"[2]	children with ADHD are able to help others more than themselves	helping others	d660 Assisting others	PF -able to help others more than themselves
	try to fulfill the needs of their family	fulfill the needs of their family	d6606 Helping in assisting others	d760 Family relationships

Table 11. Examples of linking analysis for study I (ADHD) and II (ASD) -continued

Transcript	Meaningful unit	Meaningful concept	R1	R2
"With my family doctor I have been over time slowly educating her about challenges I face, and she's been very open to learning about them and to help me find resources that…will help me better understand who I am and thus help me to understand "How do I live a positive, constructive way of life", that doesn't really depend on the pharmaceutical cure for depression, anxiety etc"[3]	she's [family doctor] been very open to learning about challenges I face	open attitude of family doctor	e450 Individual attitudes of health professionals	e450 Individual attitudes of health professionals
	help me find resources that…will help me better understand who I am and thus help me to understand "How do I live a positive, constructive way of life", that doesn't really depend on the pharmaceutical cure for depression, anxiety etc"[3]	the family doctor supports the adult with autism	e355 Health professionals	e355 Health professionals

[1]A child with ADHD from Brazil
[2]A health professional working with individuals with ADHD in Saudi Arabia
[3]An adult with ASD from Canada

Table 12. Inter-rater agreement for study I (ADHD)

Linking group	Cohen's Kappa	Standard Error	Confidence interval
Brazil	0.72	0.016	0.69-0.75
India	0.91	0.062	0.79-1.0
Saudi Arabia*	0.75	0.030	0.69-0.81
Saudi Arabia**	0.63	0.021	0.59-0.67
South Africa	0.58	0.066	0.45-0.71
Sweden***	0.75	0.030	0.69-0.81
Sweden****	0.67	0.014	0.64-0.70

*This linking group, which included only one stakeholder group from Saudi Arabia (i.e. adults), was analyzed by SM (from Sweden) and HA (from Saudi Arabia)
** This linking group, which included two stakeholder groups from Saudi Arabia (i.e. health professionals and parents), were analyzed by SM (from Sweden) and NA (from Saudi Arabia).
***This linking group, which included only one stakeholder group from Sweden (i.e. parents to adolescents), was analyzed by SM (from Sweden) and AF (from Sweden).
****This linking group, which included seven stakeholder groups from Sweden (i.e. children, adolescents, adults, parents to children, school personnel, professional caregivers and representatives from interest organizations), were analyzed by SM (from Sweden) and JH (from Sweden)

Table 13. Inter-rater agreement for study II (ASD)

Linking group	Cohen's Kappa	Standard Error	Confidence interval
Canada	0.65	0.019	0.61-0.69
India	0.72	0.018	0.68-0.76
Saudi Arabia*	0.36	0.029	0.30-0.42
Saudi Arabia**	0.48	0.030	0.42-0.53
South Africa	0.63	0.020	0.59-0.67
Sweden***	0.57	0.017	0.54-0.60
Sweden****	0.64	0.018	0.60-0.68

*This linking group, which included one stakeholder group from Saudi Arabia (i.e. professional caregivers), was analyzed by SM (from Sweden) and MA (from Saudi Arabia)
**This linking group, which included one stakeholder group from Saudi Arabia (i.e. parents), was analyzed by SM (from Sweden) and OA (from Saudi Arabia)
***This linking group, which included four stakeholder groups from Sweden (i.e. adults, parents to youth, professional caregivers and school personnel), was analyzed by SM (from Sweden) and AF (from Sweden)
****This linking group, which included four stakeholder groups from Sweden (i.e. children, adolescents, parents to children and representative from interest organizations), was analyzed by SM (from Sweden) and JH (from Sweden)

3.6.2 Study III and IV

For study III (ADHD) and IV (ASD), an ICF category that reached the score of 2 or more in the NRS in at least 10 % of the clinical cases was included as candidate category. Although a rating of 1 would be sufficient enough to classify a certain aspect as mildly impaired/barrier/facilitator/strength, a more conservative cut-off was selected to avoid margins of error. The 10 % cut-off was determined based on results from a previous ICF-CS preparatory clinical study (Vierhoff et al. 2015). Frequency analysis, both relative (%) and absolute (n), was calculated for the ICF categories that reached the score of 2 or above. Other scoring options, such as "Not applicable" or "Not specified", were excluded from the frequency analysis. Descriptive analysis was performed to summarize participants' sociodemographic background. An exploratory analysis was conducted on the personal factors, summarizing recurring concepts. In study III, personal factors were linked to a personal factors classification scheme as proposed by Grotkamp et al. (2012).

4 RESULTS

4.1 STUDY I

In total, 3021 meaningful concepts were extracted from the analysis of 16 stakeholder groups in the ADHD study. The meaningful concepts generated 82 second-level ICF categories, 243 personal factors (e.g. self-esteem, creativity, sense of humor), 152 nondefinable codes (e.g. structure, understanding, body problems), 120 not covered codes (e.g. education programs for parents, QoL, crime) and 17 health condition codes (e.g. dyslexia, ASD, anxiety). Different meaningful concepts that contained similar aspects of functioning and environment were linked to the same ICF category. For example, "my mom helps me with structure" and "my

dad does not pay attention to me" were linked to the same ICF category, namely e310 Immediate family. Categories that were identified on third and fourth-level ICF categories were aggregated to second-level categories. For example, "difficulties with impulse control [b1304 Impulse control]" and "lack of energy [b1300 Energy level]" were aggregated to the same superordinate category, i.e. b130 Energy and drive functions. The 82 unique second-level ICF categories were found across all four ICF components as followed: 32 activities and participation categories, 25 environmental factors, 23 body functions and 2 body structures. The saturation analysis (Flick, 2014) showed that only one ICF candidate category would have been missing if data was only based on transcripts from Sweden. If the study sample only comprised transcripts from diagnosed individuals, 71 (87 %) second-level ICF categories would have been covered. An additional ICF category would not have been covered if the sample was based on family members and diagnosed individuals.

4.1.1 Activities and participation

Table 14 lists all activities and participation categories that were found in the study. The 32 activities and participation categories came from all nine chapters, covering aspects related to d5 Self-care (k = 6), d1 Learning and applying knowledge (k = 5), d2 General tasks and demands (k = 5), d7 Interpersonal interactions and relationships (k = 5), d6 Domestic life (k = 4), d4 Mobility (k = 3), d8 Major life areas (k = 2), d3 Communication (k = 1) and d9 Community, social and civic life (k = 1).

Table 14. Second-level ICF categories in the activities and participation component

Second-level ICF category	Chapter-level ICF category	N
d160 Focusing attention	d1 Learning and applying knowledge	7
d161 Directing attention	d1 Learning and applying knowledge	7
d172 Calculating	d1 Learning and applying knowledge	5
d175 Solving problems	d1 Learning and applying knowledge	4
d177 Making decisions	d1 Learning and applying knowledge	4
d210 Undertaking a single task	d2 General tasks and demands	12
d220 Undertaking multiple tasks	d2 General tasks and demands	6
d230 Carrying out daily routine	d2 General tasks and demands	10
d240 Handling stress and other psychological demands	d2 General tasks and demands	9
d250 Managing one's own behaviour	d2 General tasks and demands	11
d310 Communicating with -receiving - spoken messages	d3 Communication	3
d440 Fine hand use	d4 Mobility	5
d455 Moving around	d4 Mobility	6
d470 Using transportation	d4 Mobility	5
d510 Washing oneself	d5 Self-care	4
d520 Caring for body parts	d5 Self-care	6
d530 Toileting	d5 Self-care	3
d540 Dressing	d5 Self-care	5

Table 14. Second-level ICF categories in the activities and participation component - continued

Second-level ICF category	Chapter-level ICF category	N
d570 Looking after one's health	d5 Self-care	8
d571 Looking after one's safety	d5 Self-care	4
d630 Preparing meals	d6 Domestic life	3
d640 Doing housework	d6 Domestic life	6
d650 Caring for household objects	d6 Domestic life	5
d660 Assisting others	d6 Domestic life	6
d710 Basic interpersonal interactions	d7 Interpersonal interactions and relationships	5
d720 Complex interpersonal interactions	d7 Interpersonal interactions and relationships	13
d740 Formal relationships	d7 Interpersonal interactions and relationships	4
d750 Informal social relationships	d7 Interpersonal interactions and relationships	9
d760 Family relationships	d7 Interpersonal interactions and relationships	6
d820 School education	d8 Major life areas	12
d880 Engagement in play	d8 Major life areas	3
d920 Recreation and leisure	d9 Community, social and civic life	13

Several aspects of activities and participation were mentioned by the participants. An adult with ADHD from Saudi Arabia talked about coping with general tasks and demands in everyday life: *"Personal experience, waking up early, being on time, big problem, today is an exception. I have forgotten things that are important before. Forgetfulness is important. Getting any chore done, renewing licenses, no matter how simple the task is, the very idea of doing something so boring makes me have to plan it so I can reward myself after. It becomes a very difficult ordeal, it takes a lot of effort, it kind of drains you".*

An adult with ADHD from Sweden talked about dealing with self-care and domestic life issues: *"Cleaning is a big concern for me. I also have kids, so sometimes I feel that I am a bad parent, because you need to remember to brush your teeth, but also remind your kids about it. That becomes too difficult for me".*

A parent from Saudi Arabia addressed certain aspects related to social interactions: *"She has her own unique personality that makes everyone love her, yet she can't make friendship with children of her age. They don't like her because she bites them when they don't play the way she prefers. Sometimes she even bites me".*

4.1.2 Environmental factors

Table 15 shows all environmental factors categories that were identified in the study. The 25 environmental factors represented all five chapters, including e4 Attitudes (k = 8), e3 Support and relationships (k = 7), e1 Products and technology (k = 5), e5 Services, systems and policies (k = 4) and e2 Natural environment and human-made changes to environment (k = 1).

Table 15. Second-level ICF categories in the environmental factor component

Second-level ICF category	Chapter-level ICF category	N
e110 Products or substances for personal consumption	e1 Products and technology	14
e115 Products and technology for personal use in daily living	e1 Products and technology	12
e125 Products and technology for communication	e1 Products and technology	8
e130 Products and technology for education	e1 Products and technology	4
e140 Products and technology for culture, recreation and sport	e1 Products and technology	2
e250 Sound	e2 Natural environment and human-made changes to environment	7
e310 Immediate family	e3 Support and relationships	14
e315 Extended family	e3 Support and relationships	3
e320 Friends	e3 Support and relationships	9
e325 Acquaintances, peers, colleagues, neighbours and community members	e3 Support and relationships	10
e330 People in positions of authority	e3 Support and relationships	6
e340 Personal care providers and personal assistants	e3 Support and relationships	7
e360 Other professionals	e3 Support and relationships	10
e410 Individual attitudes of immediate family members	e4 Attitudes	8
e415 Individual attitudes of extended family members	e4 Attitudes	3
e420 Individual attitudes of friends	e4 Attitudes	5
e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	e4 Attitudes	7
e430 Individual attitudes of people in positions of authority	e4 Attitudes	7
e440 Individual attitudes of people in positions of authority	e4 Attitudes	4
e455 Individual attitudes of other professionals	e4 Attitudes	6
e460 Societal attitudes	e4 Attitudes	7
e580 Health services, systems and policies	e5 Services, systems and policies	4
e585 Education and training services, systems and policies	e5 Services, systems and policies	10
e590 Labour and employment services, systems and policies	e5 Services, systems and policies	4
e595 Political services, systems and policies	e5 Services, systems and policies	3

The environmental factors that were mentioned by the different stakeholder groups could either facilitate or hinder individual outcome in functioning. An adolescent with ADHD from Brazil emphasized the role that supportive figures in life can have on individual functioning: *"My mother, she helps me with the medication. She gives me many advices too. She knows my problems. She sees that I lack attention and instead of fighting me, she gives me instructions"*.

A parent from Saudi Arabia talked about how lack of awareness and knowledge about ADHD can negatively influence school outcome: *"The school is not well-prepared for kids with ADHD and the teachers doesn't have enough background of this disorder. They don't understand how to deal with him, they deal with him as a naughty student and put burden on him by asking him to be more committed as other normal kids in the classroom. The curriculums are difficult for him as he is expected to be at the same level of other children"*.

An adult person with ADHD from Saudi Arabia stressed the importance of being in an environment that facilitates occupational functioning: *"A great boss and a great environment really affects. When I'm at a professional environment where everyone knows what to do and their responsibilities, this is a great environment for me. So this job really affected me in a good way. I need to go somewhere where they can push me. Stimulation is the key, whether its people or things. People who can support me emotionally and who are open is what helps me."*

A representative from an interest organization in Sweden talked about the need for service providers to be more receptive to individual needs and avoid allocating resources based on diagnostic labels: *"The support that is being offered by different service providers in society are not adapted to the situation of parents and individuals. They offer support that is too general, focusing on diagnostic labels rather than individual needs"*.

4.1.3 Body functions and structures

Table 16 represents all second-level ICF categories that were identified in the body functions component. Body functions came mainly from b1 Mental functions chapter (k = 16), followed by b4 Functions of the cardiovascular, hematological, immunological and respiratory systems (k = 2), b5 Functions of the digestive, metabolic and endocrine systems (k = 2), b7 Neuromusculoskeletal and movement-related functions (k = 2) and b2 Sensory functions and pain (k = 1).

Table 16. Second-level ICF categories in the body functions component

Second-level ICF category	Chapter-level ICF category	N
b114 Orientation functions	b1 Mental functions	3
b117 Intellectual functions	b1 Mental functions	5
b122 Global psychosocial functions	b1 Mental functions	4
b125 Dispositions and intra-personal functions	b1 Mental functions	6
b126 Temperament and personality functions	b1 Mental functions	15
b130 Energy and drive functions	b1 Mental functions	14
b134 Sleep functions	b1 Mental functions	9
b140 Attention functions	b1 Mental functions	16
b144 Memory functions	b1 Mental functions	15
b147 Psychomotor functions	b1 Mental functions	16
b152 Emotional functions	b1 Mental functions	14
b156 Perceptual functions	b1 Mental functions	5
b160 Thought functions	b1 Mental functions	10
b164 Higher-level cognitive functions	b1 Mental functions	12
b167 Mental functions of language	b1 Mental functions	3
b180 Experience of self and time functions	b1 Mental functions	7
b280 Sensation of pain	b2 Sensory functions and pain	11
b410 Heart functions	b4 Functions of the cardiovascular, hematological, immunological and respiratory systems	4
b455 Exercise tolerance functions	b4 Functions of the cardiovascular, hematological, immunological and respiratory systems	4
b530 Weight maintenance functions	b5 Functions of the digestive, metabolic and endocrine systems	4
b535 Sensations associated with the digestive system	b5 Functions of the digestive, metabolic and endocrine systems	3
b760 Control of voluntary movement functions	b7 Neuromusculoskeletal and movement-related functions	10
b765 Involuntary movement functions	b7 Neuromusculoskeletal and movement-related functions	3

Regarding body structures component, only two second-level ICF categories were identified, namely s110 Structure of brain (n = 5) and s710 Structure of head and neck region (n = 5).

4.1.4 Personal factors

The linking analysis yielded 243 personal factors with considerable variation in concepts. The majority of the concepts were perceived as facilitating factors for individual functioning. Some were related to personality traits (e.g. kindness, stubbornness, affectionate) and personal attitudes and interests (e.g. special interests, listening to music), whereas others

pertained to life habits (e.g. having a hobby, enjoying physical exercises) and behavior patterns (e.g. coping strategies).

A health professional from Saudi Arabia talked about the importance of establishing life habits for individuals with ADHD: *"It is necessary for them to have hobbies like photography and football. The more they put their interest in something and find support they will feel successful. When a child is interested in football for instance, they will achieve better in their daily life compared to a child who doesn't have a hobby. Hobbies encourage the child to deal well with his daily routine".*

An adult from Sweden discussed certain behavior patterns that helped with coping with stressors in life: *"I have learnt mindfulness to control my stress. When I am stressed, everything becomes twice as difficult at work. So I use a lot of mindfulness to relax. I take 5 minutes of microbreaks to just breathe, and then I am good to go".*

4.1.5 ADHD-related strengths

Most of the study participants (n = 54, 71 %) mentioned one or several strengths associated with ADHD. The skill sets and abilities that were mentioned by the participants were very broad and diverse, but some recurring themes and categories were identified. The b130 Energy and drive functions (n = 11) was one such category, which was mentioned to facilitate engagement in physical sport activities (e.g. swimming, football) as well as achieving personal goals and coping with general tasks and demands in life (e.g. completing deadlines for assignments or study before exams). Creativity (n = 7) was another strength that was linked with ADHD, enabling individuals to think outside of the box and generate solutions to novel solutions. Creativity was also mentioned in the context of special interests and crafting. Furthermore, d161 Directing attention (n = 5) was highlighted in the various stakeholder groups as a significant strength associated with ADHD, with individuals hyper-focusing on specific tasks or activities that were of particular interest to them. Finally, b126 Temperament and personality functions (n = 5) was commonly identified in the stakeholder groups, with participants attributing certain personality traits to individuals with ADHD, such as agreeableness and curiosity.

4.2 STUDY II

The linking of 19 stakeholder groups in the ASD study generated in total 4146 meaningful concepts, which were linked to 110 unique second-level ICF categories, 492 personal factors (e.g. honesty, self-esteem, age, sense of humor), 223 not covered codes (e.g. procrastination, lunch breaks, self-harming behaviors), 209 nondefinable codes (e.g. strategies, structure, routines) and 26 health condition codes (e.g. ADHD, depression, obsessive compulsive disorder). The 110 second-level ICF categories represented all four components: 45 activities and participation categories, 33 body functions, 29 environmental factors and 3 body structures. The results from the saturation analysis (Flick, 2014) showed that 20 (18 %) second-level ICF categories would have been uncovered if data only relied on information from autistic individuals, hence emphasizing the necessity of involving other types of

stakeholders. Further analysis revealed that two (2 %) ICF categories would have been missing if results were only based on findings from the Swedish study site.

4.2.1 Activities and participation

Table 17 summarizes all the categories that were covered in the activities and participation component. Specifically, these represented all nine chapters of the activities and participation component: d3 Communication (k = 7), d1 Learning and applying knowledge (k = 6), d5 Self-care (k = 6), d8 Major life areas (k = 6), d4 Mobility (k = 5), d7 Interpersonal interactions and relationships (k = 5), d2 General tasks and demands (k = 4), d6 Domestic life (k = 3) and d9 Community, social and civic life (k = 3).

Table 17. Second-level ICF categories in the activities and participation component

Second-level ICF category	Chapter-level ICF category	N
d130 Copying	d1 Learning and applying knowledge	7
d132 Acquiring information	d1 Learning and applying knowledge	5
d161 Directing attention	d1 Learning and applying knowledge	4
d166 Reading	d1 Learning and applying knowledge	8
d172 Calculating	d1 Learning and applying knowledge	5
d177 Making decisions	d1 Learning and applying knowledge	5
d210 Undertaking a single task	d2 General tasks and demands	10
d230 Carrying out daily routine	d2 General tasks and demands	18
d240 Handling stress and other psychological demands	d2 General tasks and demands	8
d250 Managing one's own behaviour	d2 General tasks and demands	12
d310 Communicating with -receiving - spoken messages	d3 Communication	9
d315 Communicating with -receiving - nonverbal messages	d3 Communication	6
d330 Speaking	d3 Communication	12
d335 Producing nonverbal messages	d3 Communication	16
d345 Writing messages	d3 Communication	5
d350 Conversation	d3 Communication	8
d360 Using communication devices and techniques	d3 Communication	4
d440 Fine hand use	d4 Mobility	12
d446 Fine foot use	d4 Mobility	6
d455 Moving around	d4 Mobility	7
d470 Using transportation	d4 Mobility	7
d475 Driving	d4 Mobility	6
d510 Washing oneself	d5 Self-care	8
d520 Caring for body parts	d5 Self-care	11
d530 Toileting	d5 Self-care	9
d540 Dressing	d5 Self-care	10
d550 Eating	d5 Self-care	9

Table 17. Second-level ICF categories in the activities and participation component - continued

Second-level ICF category	Chapter-level ICF category	N
d570 Looking after one's health	d5 Self-care	12
d620 Acquisition of goods and services	d6 Domestic life	5
d630 Preparing meals	d6 Domestic life	1
d640 Doing housework	d6 Domestic life	4
d710 Basic interpersonal interactions	d7 Interpersonal interactions and relationships	16
d720 Complex interpersonal interactions	d7 Interpersonal interactions and relationships	18
d740 Formal relationships	d7 Interpersonal interactions and relationships	7
d750 Informal social relationships	d7 Interpersonal interactions and relationships	16
d760 Family relationships	d7 Interpersonal interactions and relationships	7
d820 School education	d8 Major life areas	16
d845 Acquiring, keeping and terminating a job	d8 Major life areas	4
d850 Remunerative employment	d8 Major life areas	5
d860 Basic economic transactions	d8 Major life areas	5
d870 Economic self-sufficiency	d8 Major life areas	1
d880 Engagement in play	d8 Major life areas	4
d910 Community life	d9 Community, social and civic life	5
d920 Recreation and leisure	d9 Community, social and civic life	17
d940 Human rights	d9 Community, social and civic life	1

Different aspects of activities and participation were mentioned by the participants in the various stakeholder groups, including social interaction and participation in social activities, as demonstrated by the following quote from a school personnel working in Sweden: *"When [referring to individuals with ASD] they meet new people, they get questions that they don't know how to answer. Many individuals learn certain patterns of behaviors, some better than others. It takes time, but sometimes you see individuals trying to imitate a certain situation or social behavior. It becomes too mechanistic though, given that they don't understand the meaning of social exchanges. We work very hard to get these individuals to open up and trust other people, but small chats are not really the strength of these individuals. They don't really go out to enjoy themselves. They don't participate in social activities either. In extreme cases, they only interact with friends whom they have found through the Internet".*

An adult person with ASD from Canada talked about issues in managing personal finances: *"Challenges me a great deal when it comes to managing my personal finances. And I'm having a great deal of difficulty explaining this to people that I thought would be able to help me. They all seem to think with a little bit more education in the matter, I should be able to handle this on my own. And to a certain extent, I can see with a little more education I might be able to handle the actual aspect of going and appropriately purchasing items. But I would still be looking to someone else in my life, or someone else plural, in my life to do things like*

help me draw up a budget and ensure that I haven't overspent in any one particular category, because those aspects of mathematics don't agree with me."

A parent from India discussed challenges that her child with ASD faced when using public transportation: *"The problem with him is he doesn't like to go by train. I have to make endless schedules for that, that you have to sit like this, do like this etc. He is so scared of the noise of train that it is very difficult for me to make him travel in train but once he sits in the train, then he becomes okay. Just the noise makes him uneasy."*

4.2.2 Environmental factors

Table 18 details all the categories that were identified in the environmental factor component. All five environmental chapters were covered in the study as followed: e4 Attitudes (k = 8), e3 Support and relationships (k = 7), e5 Services, systems and policies (k = 7), e1 Products and technology (k = 4) and e2 Natural environment and human-made changes to environment (k = 3).

Table 18. Second-level ICF categories in the environmental factor component

Second-level ICF category	Chapter-level ICF category	N
e110 Products or substances for personal consumption	e1 Products and technology	6
e115 Products and technology for personal use in daily living	e1 Products and technology	15
e125 Products and technology for communication	e1 Products and technology	12
e130 Products and technology for education	e1 Products and technology	6
e240 Light	e2 Natural environment and human-made changes to environment	6
e250 Sound	e2 Natural environment and human-made changes to environment	14
e260 Air quality	e2 Natural environment and human-made changes to environment	1
e310 Immediate family	e3 Support and relationships	17
e320 Friends	e3 Support and relationships	5
e325 Acquaintances, peers, colleagues, neighbours and community members	e3 Support and relationships	6
e330 People in positions of authority	e3 Support and relationships	9
e340 Personal care providers and personal assistants	e3 Support and relationships	9
e355 Health professionals	e3 Support and relationships	8
e360 Other professionals	e3 Support and relationships	12
e410 Individual attitudes of immediate family members	e4 Attitudes	15

Table 18. Second-level ICF categories in the environmental factor component -continued

Second-level ICF category	Chapter-level ICF category	N
e415 Individual attitudes of extended family members	e4 Attitudes	1
e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	e4 Attitudes	5
e430 Individual attitudes of people in positions of authority	e4 Attitudes	7
e450 Individual attitudes of health professionals	e4 Attitudes	4
e455 Individual attitudes of other professionals	e4 Attitudes	5
e460 Societal attitudes	e4 Attitudes	8
e465 Social norms, ideologies and practices	e4 Attitudes	1
e550 Legal services, systems and policies	e5 Services, systems and policies	1
e560 Media services, systems and policies	e5 Services, systems and policies	3
e570 Social security services, systems and policies	e5 Services, systems and policies	2
e575 General social support services, systems and policies	e5 Services, systems and policies	5
e580 Health services, systems and policies	e5 Services, systems and policies	8
e585 Education and training services, systems and policies	e5 Services, systems and policies	17
e590 Labour and employment services, systems and policies	e5 Services, systems and policies	5

Products and technology were usually mentioned by participants to facilitate everyday life functioning. A parent from Canada recommended using electronic devices to help with daily scheduling of activities: *"There's an app for just about everything. And I'm suggesting, frequently to families, that they look at translating the visual schedule thing and all the appointments and everything else to the iPhone and have the phone do the nagging for them. I tell them to do that"*.

Certain adaptations in school were also mentioned to facilitate functioning as remarked by an adolescent with ASD from Sweden: *"At school, we have this cellphone app that tells us what we are going to do. It's like a calendar. Ehm…I also get to do my examinations orally, which helps me quite a lot."*

A trainee parent from India talked about the importance of paying attention to sensory stimuli in the environment, which can have a profound negative impact on children with ASD: *"My*

child is affected by lights, sounds, and making a lot of noises. So she has issues within. She closes her ears and she tries to…you know to go out from the class".

Lack of peers was mentioned by a parent from South Africa to be a barrier for her son: *"One word answer, friends. I think not having friends for them is a big problem. I mean especially here…on the very long holidays like now you'll get people if you've got other family with other kids in the same age you'll hear that this one's going to go play there or that one's coming to play here. And that…there's no such interaction with my son. Nobody knocks on the door to come play at our house or he doesn't get invited to go to…yah".*

4.2.3 Body functions and structures

Table 19 shows all second-level ICF categories that were linked to the body functions component, which comprised b1 Mental functions (k = 18), b2 Sensory functions and pain (k = 7), b5 Functions of the digestive, metabolic and endocrine systems (k = 4), b7 Neuromusculoskeletal and movement-related functions (k = 3) and b4 Functions of the cardiovascular, hematological, immunological and respiratory systems (k = 1).

Table 19. Second-level ICF categories in the body functions component

Second-level ICF category	Chapter-level ICF category	N
b114 Orientation functions	b1 Mental functions	5
b117 Intellectual functions	b1 Mental functions	6
b122 Global psychosocial functions	b1 Mental functions	4
b125 Dispositions and intra-personal functions	b1 Mental functions	15
b126 Temperament and personality functions	b1 Mental functions	14
b130 Energy and drive functions	b1 Mental functions	13
b134 Sleep functions	b1 Mental functions	12
b140 Attention functions	b1 Mental functions	12
b144 Memory functions	b1 Mental functions	14
b147 Psychomotor functions	b1 Mental functions	13
b152 Emotional functions	b1 Mental functions	15
b156 Perceptual functions	b1 Mental functions	8
b160 Thought functions	b1 Mental functions	10
b163 Basic cognitive functions	b1 Mental functions	7
b164 Higher-level cognitive functions	b1 Mental functions	18
b167 Mental functions of language	b1 Mental functions	10
b172 Calculation functions	b1 Mental functions	3
b180 Experience of self and time functions	b1 Mental functions	4
b210 Seeing functions	b2 Sensory functions and pain	4
b230 Hearing functions	b2 Sensory functions and pain	11
b250 Taste function	b2 Sensory functions and pain	6
b255 Smell function	b2 Sensory functions and pain	5
b265 Touch function	b2 Sensory functions and pain	10

Table 19. Second-level ICF categories in the body functions component -continued

Second-level ICF category	Chapter-level ICF category	N
b270 Sensory functions related to temperature and other stimuli	b2 Sensory functions and pain	7
b280 Sensation of pain	b2 Sensory functions and pain	14
b455 Exercise tolerance functions	b4 Functions of the cardiovascular, hematological, immunological and respiratory systems	4
b510 Ingestion functions	b5 Functions of the digestive, metabolic and endocrine systems	4
b515 Digestive functions	b5 Functions of the digestive, metabolic and endocrine systems	7
b525 Defecation functions	b5 Functions of the digestive, metabolic and endocrine systems	4
b530 Weight maintenance functions	b5 Functions of the digestive, metabolic and endocrine systems	3
b760 Control of voluntary movement functions	b7 Neuromusculoskeletal and movement-related functions	13
b765 Involuntary movement functions	b7 Neuromusculoskeletal and movement-related functions	9
b770 Gait pattern functions	b7 Neuromusculoskeletal and movement-related functions	6

Only three second-level ICF categories were identified from the body structures component, namely s110 Structure of brain (n = 9), s320 Structure of mouth (n = 4) and s750 Structure of lower extremity (n = 4).

4.2.4 Personal factors

The linking analysis generated 492 personal factors. An overwhelming majority of the personal factors were perceived to facilitate individual functioning. There was a substantial variation in concepts that were mentioned by the different stakeholder groups. Some were related to personality factors (e.g. empathetic, great sense of right and wrong) and life habits (e.g. playing with technical devices, listening to music), whereas others pertained to own personal attitudes (e.g. acceptance of own diagnosis, seeing the good in other people) and behavior patterns (e.g. trying new things, accepting challenges).

A child with ASD from Sweden: *"I stay calm and don't pay attention to disturbing noises or people. I try to focus on positive things, see the good in other people".*

An adult with ASD from Sweden: *"I am stubborn and I want to do things that are perceived as difficult. I accept challenges and I try to function as normal as possible."*

An adult with ASD from India: *"We are proud to be different. We are sufficient for ourselves, what can we do about what people think of us?"*

4.2.5 ASD-related strengths

Participants mentioned certain strengths associated with ASD, albeit these were quite diverse. Some recurring themes and categories included b126 Temperament and personality functions (n = 8) as expressed by an adult with ASD: *"Honesty is something I like. If you do something, you should be able to stand for it. I am very frank with everything I do. I don't sugarcoat things. I often say what I think"*.

A professional emphasized attention (b140 Attention functions; n = 6) and out of box thinking (n = 5): *"Their intense focus. Their ability to maintain focus is a strong positive trait, as well as thinking outside of the box, which can be beneficial when they are facing situations which require novel solutions"*.

A parent to a child with ASD talked about memory (b144 Memory functions; n = 5) as a strength: *"The visual memory is good. He can remember English glossary. He has the capacity to remember things"*.

Other recurring strengths included d166 Reading (n = 3) and expertise in a specific topic (n = 3).

4.3 STUDY III

When applying the 10 % cut-off in the ADHD clinical study, 113 second-level ICF candidate categories were identified. Saturation analysis (Flick, 2014) indicated that no categories would have been lost if data was only based on sample from Europe. Of the 113 categories that reached the 10 % cut-off, 50 were activities and participation, 33 were environmental factors and 30 were body functions. No body structures reached the 10 % cut-off.

4.3.1 Activities and participation

The 50 activities and participation categories represented all nine chapters, specifically d1 Learning and applying knowledge (k = 12), d5 Self-care (k = 7), d7 Interpersonal interactions and relationships (k = 7), d2 General tasks and demands (k = 5), d3 Communication (k = 5), d4 Mobility (k = 4), d6 Domestic life (k = 4), d8 Major life areas (k = 4) and d9 Community, social and civic life (k = 2). Table 20 shows all the second-level ICF categories that were captured in the activities and participation component along with their absolute and relative frequencies.

Table 20. Second-level ICF categories in the activities and participation component

Second-level ICF category	Chapter-level ICF category	N (%)
d110 Watching	d1 Learning and applying knowledge	16 (14)
d115 Listening	d1 Learning and applying knowledge	29 (25)
d140 Learning to read	d1 Learning and applying knowledge	27 (24)
d145 Learning to write	d1 Learning and applying knowledge	26 (23)
d150 Learning to calculate	d1 Learning and applying knowledge	29 (25)
d160 Focusing attention	d1 Learning and applying knowledge	102 (91)
d161 Directing attention	d1 Learning and applying knowledge	102 (91)
d166 Reading	d1 Learning and applying knowledge	46 (41)
d170 Writing	d1 Learning and applying knowledge	46 (41)
d172 Calculating	d1 Learning and applying knowledge	50 (44)
d175 Solving problems	d1 Learning and applying knowledge	58 (51)
d177 Making decisions	d1 Learning and applying knowledge	59 (52)
d210 Undertaking a single task	d2 General tasks and demands	72 (64)
d220 Undertaking multiple tasks	d2 General tasks and demands	91 (81)
d230 Carrying out daily routine	d2 General tasks and demands	80 (71)
d240 Handling stress and other psychological demands	d2 General tasks and demands	74 (66)
d250 Managing one's own behaviour	d2 General tasks and demands	77 (68)
d310 Communicating with -receiving - spoken messages	d3 Communication	31 (27)
d315 Communicating with -receiving - nonverbal messages	d3 Communication	32 (28)
d330 Speaking	d3 Communication	32 (28)
d335 Producing nonverbal messages	d3 Communication	20 (17)
d350 Conversation	d3 Communication	55 (49)
d440 Fine hand use	d4 Mobility	34 (30)
d446 Fine foot use	d4 Mobility	20 (17)
d470 Using transportation	d4 Mobility	15 (13)
d475 Driving	d4 Mobility	22 (19)
d510 Washing oneself	d5 Self-care	26 (23)
d520 Caring for body parts	d5 Self-care	34 (30)
d530 Toileting	d5 Self-care	20 (17)
d540 Dressing	d5 Self-care	18 (16)
d550 Eating	d5 Self-care	18 (16)
d570 Looking after one's health	d5 Self-care	52 (46)
d571 Looking after one's safety	d5 Self-care	49 (43)
d620 Acquisition of goods and services	d6 Domestic life	35 (31)
d630 Preparing meals	d6 Domestic life	31 (27)
d640 Doing housework	d6 Domestic life	51 (45)
d660 Assisting others	d6 Domestic life	25 (22)
d710 Basic interpersonal interactions	d7 Interpersonal interactions and relationships	54 (48)

Table 20. Second-level ICF categories in the activities and participation component - continued

Second-level ICF category	Chapter-level ICF category	N (%)
d720 Complex interpersonal interactions	d7 Interpersonal interactions and relationships	71 (63)
d730 Relating with strangers	d7 Interpersonal interactions and relationships	23 (20)
d740 Formal relationships	d7 Interpersonal interactions and relationships	37 (33)
d750 Informal social relationships	d7 Interpersonal interactions and relationships	38 (33)
d760 Family relationships	d7 Interpersonal interactions and relationships	44 (39)
d770 Intimate relationships	d7 Interpersonal interactions and relationships	32 (28)
d820 School education	d8 Major life areas	32 (28)
d850 Remunerative employment	d8 Major life areas	21 (18)
d870 Economic self-sufficiency	d8 Major life areas	27 (24)
d880 Engagement in play	d8 Major life areas	17 (15)
d910 Community life	d9 Community, social and civic life	15 (13)
d920 Recreation and leisure	d9 Community, social and civic life	42 (37)

4.3.2 Environmental factors

The 33 categories in the environmental factors component were distributed across all five chapters as followed: e3 Support and relationships (k = 8), e4 Attitudes (k = 8), e5 Services, systems and policies (k = 8), e1 Products and technology (k = 6) and e2 Natural environment and human-made changes to environment (k = 3). Table 21 represents all the second-level ICF categories that reached the 10 % cut-off in the environmental factor component along with their absolute and relative frequencies.

Table 21. Second-level ICF categories in the environmental factor component

Second-level ICF category	Chapter-level ICF category	N (%)
e110 Products or substances for personal consumption	e1 Products and technology	72 (64)
e115 Products and technology for personal use in daily living	e1 Products and technology	77 (68)
e120 Products and technology for indoor and outdoor mobility and transportation	e1 Products and technology	29 (25)
e125 Products and technology for communication	e1 Products and technology	58 (51)
e130 Products and technology for education	e1 Products and technology	28 (25)
e165 Assets	e1 Products and technology	23 (20)
e225 Climate	e2 Natural environment and human-made changes to environment	35 (31)
e240 Light	e2 Natural environment and human-made changes to environment	42 (37)
e250 Sound	e2 Natural environment and human-made changes to environment	51 (45)
e310 Immediate family	e3 Support and relationships	95 (84)
e315 Extended family	e3 Support and relationships	38 (33)
e320 Friends	e3 Support and relationships	65 (58)
e325 Acquaintances, peers, colleagues, neighbours and community members	e3 Support and relationships	38 (33)
e330 People in positions of authority	e3 Support and relationships	59 (52)
e340 Personal care providers and personal assistants	e3 Support and relationships	19 (16)
e355 Health professionals	e3 Support and relationships	81 (72)
e360 Other professionals	e3 Support and relationships	40 (35)
e410 Individual attitudes of immediate family members	e4 Attitudes	88 (78)
e420 Individual attitudes of friends	e4 Attitudes	56 (50)
e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	e4 Attitudes	36 (32)
e440 Individual attitudes of personal care providers and personal assistants	e4 Attitudes	15 (13)
e450 Individual attitudes of health professionals	e4 Attitudes	71 (63)
e455 Individual attitudes of other professionals	e4 Attitudes	29 (25)
e460 Societal attitudes	e4 Attitudes	53 (47)
e465 Social norms, practices and ideologies	e4 Attitudes	51 (45)

Table 21. Second-level ICF categories in the environmental factor component -continued

Second-level ICF category	Chapter-level ICF category	N (%)
e535 Communication services, systems and policies	e5 Services, systems and policies	40 (35)
e540 Transportation services, systems and policies	e5 Services, systems and policies	13 (11)
e550 Legal services, systems and policies	e5 Services, systems and policies	19 (16)
e570 Social security services, systems and policies	e5 Services, systems and policies	28 (25)
e575 General social support services, systems and policies	e5 Services, systems and policies	18 (16)
e580 Health services, systems and policies	e5 Services, systems and policies	77 (68)
e585 Education and training services, systems and policies	e5 Services, systems and policies	33 (29)
e590 Labour and employment services, systems and policies	e5 Services, systems and policies	25 (22)

4.3.3 Body functions

The 30 categories in the body functions component were mainly from the b1 Mental functions chapter (k = 16), but other areas of body functions were also represented, such as b2 Sensory functions and pain (k = 4), b7 Neuromusculoskeletal and movement-related functions (k = 4), b5 Functions of the digestive, metabolic and endocrine systems (k = 3), b3 Voice and speech functions (k = 1), b4 Functions of the cardiovascular, hematological, immunological and respiratory systems (k = 1) and b6 Genitourinary and reproductive functions (k = 1). Table 22 lists all the second-level ICF categories from the body functions component along with their absolute and relative frequencies.

Table 22. Second-level ICF categories in the body functions component

Second-level ICF category	Chapter-level ICF category	N (%)
b114 Orientation functions	b1 Mental functions	32 (28)
b122 Global psychosocial functions	b1 Mental functions	53 (47)
b125 Dispositions and intra-personal functions	b1 Mental functions	67 (59)
b126 Temperament and personality functions	b1 Mental functions	61 (54)
b130 Energy and drive functions	b1 Mental functions	64 (57)
b134 Sleep functions	b1 Mental functions	49 (43)
b140 Attention functions	b1 Mental functions	108 (96)
b144 Memory functions	b1 Mental functions	71 (63)
b147 Psychomotor functions	b1 Mental functions	63 (56)
b152 Emotional functions	b1 Mental functions	75 (66)
b156 Perceptual functions	b1 Mental functions	24 (21)
b160 Thought functions	b1 Mental functions	50 (44)
b163 Basic cognitive functions	b1 Mental functions	30 (26)
b164 Higher-level cognitive functions	b1 Mental functions	79 (70)
b167 Mental functions of language	b1 Mental functions	34 (30)
b180 Experience of self and time functions	b1 Mental functions	46 (41)
b230 Hearing functions	b2 Sensory functions and pain	12 (10)
b235 Vestibular functions	b2 Sensory functions and pain	21 (18)
b265 Touch function	b2 Sensory functions and pain	27 (24)
b280 Sensation of pain	b2 Sensory functions and pain	34 (30)
b330 Fluency and rhythm of speech functions	b3 Voice and speech functions	27 (24)
b440 Respiration functions	b4 Functions of the cardiovascular, hematological, immunological and respiratory systems	12 (10)
b525 Defecation functions	b5 Functions of the digestive, metabolic and endocrine systems	13 (11)
b530 Weight maintenance functions	b5 Functions of the digestive, metabolic and endocrine systems	29 (25)
b535 Sensations associated with the digestive system	b b5 Functions of the digestive, metabolic and endocrine systems	20 (17)
b640 Sexual functions	b6 Genitourinary and reproductive functions	18 (16)
b710 Mobility of joint functions	b7 Neuromusculoskeletal and movement-related functions	14 (12)
b735 Muscle tone functions	b7 Neuromusculoskeletal and movement-related functions	27 (24)
b760 Control of voluntary movement functions	b7 Neuromusculoskeletal and movement-related functions	33 (29)

Table 22. Second-level ICF categories in the body functions component -continued

Second-level ICF category	Chapter-level ICF category	N (%)
b765 Involuntary movement functions	b7 Neuromusculoskeletal and movement-related functions	17 (15)

4.3.4 Personal factors

The study sample generated 212 meaningful concepts pertinent to personal factors. These were linked to 30 personal factors codes in the Grotkamp et al. (2012) classification system. Table 23 lists all the personal factors codes that were identified in the study along with their absolute frequencies. The personal factors were mentioned to either facilitate or reduce functioning status of individuals.

Table 23. Second-level personal factors codes as classified by Grotkamp et al. (2012)

Second-level category	Chapter	N
i120 Sex	i1 General personal characteristics	1
i310 Extraversion	i3 Mental factors	5
i315 Factors of emotionality	i3 Mental factors	6
i320 Reliability	i3 Mental factors	5
i325 Openness to new experiences	i3 Mental factors	6
i330 Affability	i3 Mental factors	7
i335 Self-confidence	i3 Mental factors	4
i340 Optimism	i3 Mental factors	5
i350 Intelligence-related factors	i3 Mental factors	7
i355 Cognitive factors	i3 Mental factors	3
i410 World view	i4 Attitudes	2
i416 Attitude toward health and disease	i4 Attitudes	3
i419 Attitude toward intervention and health-related assistance	i4 Attitudes	1
i428 Attitude toward help	i4 Attitudes	4
i430 Social skills	i4 Attitudes	6
i433 Methodical skills	i4 Attitudes	7
i436 Empowerment	i4 Attitudes	18
i439 Proaction	i4 Attitudes	5
i442 Media skills	i4 Attitudes	1
i453 Habitual use of stimulants	i4 Attitudes	3
i456 Exercise habits	i4 Attitudes	2
i459 Relaxation habits	i4 Attitudes	1
i510 Living arrangements	i5 Life situation and socioeconomic/sociocultural factors	5
i515 Accommodation arrangements	i5 Life situation and socioeconomic/sociocultural factors	1

Table 23. Second-level personal factors codes as classified by Grotkamp et al. (2012) - continued

Second-level category	Chapter	N
i520 Employment situation	i5 Life situation and socioeconomic/sociocultural factors	2
i525 Financial situation	i5 Life situation and socioeconomic/sociocultural factors	7
i530 Socioeconomic status	i5 Life situation and socioeconomic/sociocultural factors	2
i540 Belonging to groups in society	i5 Life situation and socioeconomic/sociocultural factors	2
i550 Educational status	i5 Life situation and socioeconomic/sociocultural factors	2
i610 Prior diseases, health impairments, injuries or traumas	i5 Life situation and socioeconomic/sociocultural factors	4

4.3.5 ADHD-related strengths

Table 24 summarizes the absolute and relative frequencies of ICF categories that were rated as strengths after applying the 10 % cut-off. These included categories from d7 Interpersonal interactions and relationships (k = 4), b1 Mental functions (k = 3), d1 Learning and applying knowledge (k = 3), d4 Mobility (k = 3), d6 Domestic life (k = 3), d9 Community, social and civic life (k = 3), d8 Major life areas (k = 2) and d3 Communication (k = 1).

Table 24. Absolute and relative frequencies of ADHD-related strengths

Second-level ICF category	Chapter-level ICF category	N (%)
b125 Dispositions and intra-personal functions	b1 Mental functions	20 (17)
b126 Temperament and personality functions	b1 Mental functions	27 (24)
b144 Memory functions	b1 Mental functions	14 (12)
d110 Watching	d1 Learning and applying knowledge	14 (12)
d161 Directing attention	d1 Learning and applying knowledge	13 (11)
d175 Solving problems	d1 Learning and applying knowledge	16 (14)
d335 Producing nonverbal messages	d3 Communication	14 (12)
d450 Walking	d4 Mobility	13 (11)
d455 Moving around	d4 Mobility	13 (11)
d475 Driving	d4 Mobility	13 (11)
d630 Preparing meals	d6 Domestic life	15 (13)
d640 Doing housework	d6 Domestic life	13 (11)
d660 Assisting others	d6 Domestic life	19 (16)
d730 Relating with strangers	d7 Interpersonal interactions and relationships	12 (10)

Table 24. Absolute and relative frequencies of ADHD-related strengths -continued

Second-level ICF category	Chapter-level ICF category	N (%)
d740 Formal relationships	d7 Interpersonal interactions and relationships	14 (12)
d750 Informal social relationships	d7 Interpersonal interactions and relationships	20 (17)
d760 Family relationships	d7 Interpersonal interactions and relationships	18 (16)
d810 Informal education	d8 Major life areas	12 (10)
d880 Engagement in play	d8 Major life areas	14 (12)
d920 Recreation and leisure	d9 Community, social and civic life	21 (18)
d930 Religion and spirituality	d9 Community, social and civic life	13 (11)
d950 Political life and citizenship	d9 Community, social and civic life	14 (12)

4.4 STUDY IV

In the ASD clinical study, 139 second-level ICF categories reached the 10 % cut-off, representing 64 activities and participation categories, 40 body functions and 35 environmental factors. No body structures reached the 10 % cut-off. Saturation analysis (Flick, 2014) revealed that no candidate categories would have been missing if data was only extracted from Europe.

4.4.1 Activities and participation

Table 25 covers the 64 activities and participation categories which came from all nine chapters, i.e. d1 Learning and applying knowledge (k = 14), d4 Mobility (k = 8), d5 Self-care (k = 8), d7 Interpersonal interactions and relationships (k = 7), d8 Major life areas (k = 7), d3 Communication (k = 6), d2 General tasks and demands (k = 5), d9 Community, social and civic life (k = 5) and d6 Domestic life (k = 4).

Table 25. Second-level ICF categories in the activities and participation component

Second-level ICF category	Chapter-level ICF category	N (%)
d110 Watching	d1 Learning and applying knowledge	41 (33)
d115 Listening	d1 Learning and applying knowledge	55 (45)
d130 Copying	d1 Learning and applying knowledge	56 (45)
d132 Acquiring information	d1 Learning and applying knowledge	55 (45)
d140 Learning to read	d1 Learning and applying knowledge	36 (29)
d145 Learning to write	d1 Learning and applying knowledge	37 (30)
d150 Learning to calculate	d1 Learning and applying knowledge	44 (36)
d160 Focusing attention	d1 Learning and applying knowledge	99 (81)
d161 Directing attention	d1 Learning and applying knowledge	89 (72)
d163 Thinking	d1 Learning and applying knowledge	58 (47)
d166 Reading	d1 Learning and applying knowledge	48 (39)
d172 Calculating	d1 Learning and applying knowledge	54 (44)
d175 Solving problems	d1 Learning and applying knowledge	77 (63)
d177 Making decisions	d1 Learning and applying knowledge	81 (66)
d210 Undertaking a single task	d2 General tasks and demands	80 (65)
d220 Undertaking multiple tasks	d2 General tasks and demands	86 (70)
d230 Carrying out daily routine	d2 General tasks and demands	75 (61)
d240 Handling stress and other psychological demands	d2 General tasks and demands	101 (82)
d250 Managing one's own behaviour	d2 General tasks and demands	88 (72)
d310 Communicating with -receiving - spoken messages	d3 Communication	80 (65)
d315 Communicating with -receiving - nonverbal messages	d3 Communication	87 (71)
d330 Speaking	d3 Communication	66 (54)
d335 Producing nonverbal messages	d3 Communication	89 (72)
d350 Conversation	d3 Communication	95 (77)
d360 Using communication devices and techniques	d3 Communication	51 (41)
d430 Lifting and carrying objects	d4 Mobility	22 (18)
d440 Fine hand use	d4 Mobility	51 (41)
d446 Fine foot use	d4 Mobility	28 (22)
d450 Walking	d4 Mobility	13 (10)
d455 Moving around	d4 Mobility	27 (22)
d465 Moving around using equipment	d4 Mobility	35 (28)
d470 Using transportation	d4 Mobility	37 (30)
d475 Driving	d4 Mobility	17 (13)
d510 Washing oneself	d5 Self-care	50 (40)
d520 Caring for body parts	d5 Self-care	66 (54)
d530 Toileting	d5 Self-care	35 (28)
d540 Dressing	d5 Self-care	43 (35)
d550 Eating	d5 Self-care	30 (24)
d560 Drinking	d5 Self-care	23 (18)

Table 25. Second-level ICF categories in the activities and participation component - continued

Second-level ICF category	Chapter-level ICF category	N (%)
d570 Looking after one's health	d5 Self-care	71 (58)
d571 Looking after one's safety	d5 Self-care	54 (44)
d620 Acquisition of goods and services	d6 Domestic life	47 (38)
d630 Preparing meals	d6 Domestic life	61 (50)
d640 Doing housework	d6 Domestic life	72 (59)
d660 Assisting others	d6 Domestic life	61 (50)
d710 Basic interpersonal interactions	d7 Interpersonal interactions and relationships	104 (85)
d720 Complex interpersonal interactions	d7 Interpersonal interactions and relationships	106 (86)
d730 Relating with strangers	d7 Interpersonal interactions and relationships	77 (63)
d740 Formal relationships	d7 Interpersonal interactions and relationships	79 (64)
d750 Informal social relationships	d7 Interpersonal interactions and relationships	92 (75)
d760 Family relationships	d7 Interpersonal interactions and relationships	69 (56)
d770 Intimate relationships	d7 Interpersonal interactions and relationships	30 (24)
d810 Informal education	d8 Major life areas	39 (31)
d820 School education	d8 Major life areas	58 (47)
d845 Acquiring, keeping and terminating a job	d8 Major life areas	23 (18)
d850 Remunerative employment	d8 Major life areas	23 (18)
d860 Basic economic transactions	d8 Major life areas	31 (25)
d870 Economic self-sufficiency	d8 Major life areas	19 (15)
d880 Engagement in play	d8 Major life areas	69 (56)
d910 Community life	d9 Community, social and civic life	64 (52)
d920 Recreation and leisure	d9 Community, social and civic life	83 (68)
d930 Religion and spirituality	d9 Community, social and civic life	26 (21)
d940 Human rights	d9 Community, social and civic life	32 (26)
d950 Political life and citizenship	d9 Community, social and civic life	26 (21)

4.4.2 Environmental factors

The 35 environmental factors came from all five chapters as followed: e5 Services, systems and policies (k = 9), e3 Support and relationships (k = 8), e4 Attitudes (k = 8), e1 Products and technology (k = 7) and e2 Natural environment and human-made changes to environment (k = 3). Table 26 represents all second-level ICF categories that were identified in the environmental factor component along with their absolute and relative frequencies.

Table 26. Second-level ICF categories in the environmental factor component

Second-level ICF category	Chapter-level ICF category	N (%)
e110 Products or substances for personal consumption	e1 Products and technology	38 (31)
e115 Products and technology for personal use in daily living	e1 Products and technology	59 (48)
e120 Products and technology for personal indoor and outdoor mobility and transportation	e1 Products and technology	22 (18)
e125 Products and technology for communication	e1 Products and technology	54 (44)
e150 Design, construction and building products and technology of buildings for public use	e1 Products and technology	15 (12)
e155 Design, construction and building products and technology of buildings for private use	e1 Products and technology	13 (10)
e165 Assets	e1 Products and technology	14 (11)
e225 Climate	e2 Natural environment and human-made changes to environment	31 (25)
e240 Light	e2 Natural environment and human-made changes to environment	27 (23)
e250 Sound	e2 Natural environment and human-made changes to environment	69 (56)
e310 Immediate family	e3 Support and relationships	103 (84)
e315 Extended family	e3 Support and relationships	52 (42)
e320 Friends	e3 Support and relationships	47 (38)
e325 Acquaintances, peers, colleagues, neighbours and community members	e3 Support and relationships	45 (36)
e330 People in positions of authority	e3 Support and relationships	56 (45)
e340 Personal care providers and personal assistants	e3 Support and relationships	46 (37)
e355 Health professionals	e3 Support and relationships	87 (71)
e360 Other professionals	e3 Support and relationships	57 (46)
e410 Individual attitudes of immediate family members	e4 Attitudes	93 (76)
e420 Individual attitudes of friends	e4 Attitudes	39 (31)
e425 Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	e4 Attitudes	40 (32)
e440 Individual attitudes of personal care providers and personal assistants	e4 Attitudes	38 (31)
e450 Individual attitudes of health professionals	e4 Attitudes	73 (59)

Table 26. Second-level ICF categories in the environmental factor component -continued

Second-level ICF category	Chapter-level ICF category	N (%)
e455 Individual attitudes of other professionals	e4 Attitudes	44 (36)
e460 Societal attitudes	e4 Attitudes	50 (40)
e465 Social norms, practices and ideologies	e4 Attitudes	43 (35)
e525 Housing services, systems and policies	e5 Services, systems and policies	27 (23)
e535 Communication services, systems and policies	e5 Services, systems and policies	47 (38)
e540 Transportation services, systems and policies	e5 Services, systems and policies	34 (27)
e550 Legal services, systems and policies	e5 Services, systems and policies	36 (29)
e570 Social security services, systems and policies	e5 Services, systems and policies	56 (45)
e575 General social support services, systems and policies	e5 Services, systems and policies	53 (43)
e580 Health services, systems and policies	e5 Services, systems and policies	70 (57)
e585 Education and training services, systems and policies	e5 Services, systems and policies	44 (36)
e590 Labour and employment services, systems and policies	e5 Services, systems and policies	29 (24)

4.4.3 Body functions

Table 27 shows the 40 body functions categories that were captured in the study, representing seven of eight chapters as followed: b1 Mental functions (k = 18), b2 Sensory functions and pain (k = 8), b7 Neuromusculoskeletal and movement-related functions (k = 5), b3 Voice and speech functions (k = 3), b5 Functions of the digestive, metabolic and endocrine systems (k = 3), b6 Genitourinary and reproductive functions (k = 2) and b4 Functions of the cardiovascular, hematological, immunological and respiratory systems (k = 1).

Table 27. Second-level ICF categories in the body functions component

Second-level ICF category	Chapter-level ICF category	N (%)
b114 Orientation functions	b1 Mental functions	50 (40)
b117 Intellectual functions	b1 Mental functions	39 (31)
b122 Global psychosocial functions	b1 Mental functions	108 (88)
b125 Dispositions and intra-personal functions	b1 Mental functions	106 (86)
b126 Temperament and personality functions	b1 Mental functions	95 (77)
b130 Energy and drive functions	b1 Mental functions	89 (72)
b134 Sleep functions	b1 Mental functions	48 (39)
b140 Attention functions	b1 Mental functions	105 (86)
b144 Memory functions	b1 Mental functions	48 (39)
b147 Psychomotor functions	b1 Mental functions	70 (57)
b152 Emotional functions	b1 Mental functions	100 (81)
b156 Perceptual functions	b1 Mental functions	37 (30)
b160 Thought functions	b1 Mental functions	56 (45)
b163 Basic cognitive functions	b1 Mental functions	41 (33)
b164 Higher-level cognitive functions	b1 Mental functions	91 (74)
b167 Mental functions of language	b1 Mental functions	67 (54)
b172 Calculation functions	b1 Mental functions	56 (45)
b180 Experience of self and time functions	b1 Mental functions	70 (57)
b210 Seeing functions	b2 Sensory functions and pain	21 (17)
b230 Hearing functions	b2 Sensory functions and pain	32 (26)
b235 Vestibular functions	b2 Sensory functions and pain	33 (27)
b250 Taste function	b2 Sensory functions and pain	17 (13)
b255 Smell function	b2 Sensory functions and pain	22 (18)
b265 Touch function	b2 Sensory functions and pain	36 (29)
b270 Sensory functions related to temperature and other stimuli	b2 Sensory functions and pain	39 (31)
b280 Sensation of pain	b2 Sensory functions and pain	54 (44)
b310 Voice functions	b3 Voice and speech functions	22 (18)
b320 Articulation functions	b3 Voice and speech functions	34 (27)
b330 Fluency and rhythm of speech functions	b3 Voice and speech functions	65 (53)
b435 Immunological system functions	b4 Functions of the cardiovascular, hematological, immunological and respiratory systems	18 (14)
b515 Digestive functions	b5 Functions of the digestive, metabolic and endocrine systems	14 (11)
b525 Defecation functions	b5 Functions of the digestive, metabolic and endocrine systems	22 (18)
b530 Weight maintenance functions	b5 Functions of the digestive, metabolic and endocrine systems	21 (17)

Table 27. Second-level ICF categories in the body functions component -continued

Second-level ICF category	Chapter-level ICF category	N (%)
b620 Urination functions	b6 Genitourinary and reproductive functions	14 (11)
b640 Sexual functions	b6 Genitourinary and reproductive functions	14 (11)
b710 Mobility of joint functions	b7 Neuromusculoskeletal and movement-related functions	14 (11)
b735 Muscle tone functions	b7 Neuromusculoskeletal and movement-related functions	32 (26)
b760 Control of voluntary movement functions	b7 Neuromusculoskeletal and movement-related functions	34 (27)
b765 Involuntary movement functions	b7 Neuromusculoskeletal and movement-related functions	41 (33)
b770 Gait pattern functions	b7 Neuromusculoskeletal and movement-related functions	22 (18)

4.4.4 Personal factors

The 122 cases generated 148 personal factors. These could either serve to facilitate or reduce individual functioning. Given that the study sample contained a broad variation of personal factors, these were analyzed exploratively with recurring themes summarized. Supportive personal factors included having a high IQ, acceptance towards own diagnosis and enjoying specific interests. Having a high IQ was reported to help individuals to come up with strategies which they could use to cope with everyday life challenges and stressors. Acceptance towards own diagnosis was mentioned to facilitate individuals to seek knowledge and resources to better understand their own condition, and thus adapt to the social environment. Having a special interest meant that individuals could come into contact with other people and practice their social interaction skills. Examples of special interests included sports, art and gaming. Hindering personal factors included having caregivers with psychiatric disorders, which was mentioned to increase level of stress, and thus impacting individual functioning negatively, as it exacerbated ASD symptoms. Another hampering personal factor was past traumatic life experiences, which was reported to negatively influence individual self-esteem and self-worth. Some participants mentioned perfectionism as a negative trait that hindered them from engaging and initiating new tasks and assignments in life.

4.4.5 ASD-related strengths

When applying the 10 % cut-off, only 3 ICF categories emerged as strength, which included b144 Memory functions (n = 20, 16 %), d161 Directing attention (n = 14, 11 %) and b140 Attention functions (n = 13, 10 %).

5 DISCUSSION

5.1 STUDY I

Study I was part of an international effort to develop ICF-CS for ADHD, aiming to explore the perspectives of diagnosed individuals, family members and professionals on aspects of functioning and disability pertinent to ADHD. Study I also investigated contextual factors relevant to ADHD, as well as certain skill sets and abilities associated with ADHD. Identified categories came from all four ICF components, mostly activities and participation categories and environmental factors, but also some body functions. Body structures were scarcely mentioned by the participants. A rich variety of personal factors were considered to influence everyday life functioning, and recurring themes of ADHD-related strengths were covered.

5.1.1 Activities and participation

With regards to activities and participation, categories were identified from all nine ICF chapters (i.e. learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, community, social and civic life), attesting to the heterogeneity of ADHD. It shows that ADHD is a complex condition that cannot be fully appraised by its core behavioral domains, meaning that a person with ADHD may have an entirely different profile of functioning compared to another with same diagnosis, supporting a functioning-oriented perspective on ADHD that assesses each individual uniquely rather than grouping everyone into one diagnostic entity. The chapter coverage of activities and participation differed from the ADHD scoping review (i.e. the first preparatory study in the development of ADHD ICF-CS), which aimed to investigate the research perspective on health-related functioning in ADHD. Contrary to the current study, which identified four categories from the domestic life chapter (i.e. preparing meals, doing housework, caring for household objects, assisting others), no categories were found in the scoping review. This suggests that research on ADHD and outcome measures used in assessments do not sufficiently account for domestic life issues, which is rather surprising given the conceptualization of ADHD as a life-long condition that impacts different life areas. Issues faced in the private life are important to address, as they may influence a person's ability to live independently and function as a self-reliant individual. Domestic life issues can also be detrimental to maintaining positive relationships with other household members, as unresolved conflicts or disputes about managing household choirs could disrupt social relationships and ultimately increase the individual burden. The same is true for self-care issues, which was scarcely identified in the scoping review, but more commonly mentioned by the participants in the current study. While this study did include stakeholders (i.e. clients with ADHD, family members) who were more capable of reporting on private life issues, a review conducted by Bagatell and Matson (2015) found that intervention studies targeting domestic life and self-care in individuals with NDD were limited. In the case of ADHD, it could be related to overreliance on medication to ameliorate core symptoms. Indeed, although medication can play an important role in alleviating impairment, non-invasive treatment programs (e.g.

psychoeducation, cognitive behavioral therapy) may also be warranted (Hirvikoski et al. 2011; Matheson et al. 2013) to account for challenges that extends beyond core symptom criteria, such as adaptive skills. Another factor that could explain the lack of emphasis on self-care and domestic life issues could be related to be how services are organized in society. For example, in Sweden, patients with ADHD are usually referred to the psychiatry, and not the habilitation services (Socialstyrelsen, 2014a). While habilitation services are specialized in improving skills for daily living, psychiatry are more often concerned with alleviating symptoms and comorbidities through usage of medication. Hence, certain aspects of daily living, such as self-care and domestic life, may go unnoticed in the ADHD population. Consistent with the ADHD scoping review (de Schipper et al. 2015a) and previous research (Hoza, 2007; Michielsen et al. 2015; Wehmeier et al. 2010), this study found social relationships (e.g. formal relationships, family interactions, peer contact) and leisure participation to be affected. The impact on social life seems to be extensive, as evidenced by the inclusion of five categories from the interpersonal interactions and relationships chapter. Given that social relationships and participation are crucial for social development and learning (Pinto et al. 2018; Ray et al. 2017), it is vital that professionals are equipped with user-friendly tools that enable them to assess quality of different types of social relationships (e.g. family, friends, colleagues, supervisor, etc.). The ICF can bridge this gap by offering professionals concrete means to address social relationships in a comprehensive manner, inquiring not only about ability to create and maintain relationships, but also engagement in these interactions. Major life areas were scarcely covered in this study. While school education and engagement in play were reported, occupational functioning was not, which is rather surprising given that ADHD is associated with long-term occupational disability (Fredriksen et al. 2014). However, certain aspects related to employment were captured in the study, such as creating and maintaining formal relationships, and support and attitudes of colleagues and employers. The latter could reflect a shift in how disability is viewed, with stakeholders emphasizing environmental influences on functioning rather than individual limitations. The absence of certain stakeholders (e.g. employers, colleagues) could be another factor which may explain the lack of coverage of employment issues.

5.1.2 Environmental factors

Regarding environmental factors, all five chapters were represented (i.e. products and technology, natural environment, support and relationships, attitudes, services, systems and policies), indicating that both proximal (e.g. immediate family, electronic devices) and distal environmental influences (e.g. societal attitudes, healthcare services) are important to clients with ADHD and their social environment. This study also identified larger number and broader variety of environmental factors compared to the ADHD scoping review (de Schipper et al. 2015a), which only covered five categories in total. The results suggest that environmental factors are more important to clients with ADHD and their caregivers. The results could also reflect a lack of a biopsychosocial model in research when appraising ADHD, with greater focus on individual impairments or deficits rather than complementing these with descriptions of environmental facilitators and barriers. A major barrier has been

the absence of a classification system that utilizes a biopsychosocial framework, but with the development of ICF, stakeholders can derive user-friendly tools from the classification system to design outcome measures that take environmental influences into account. These measures can serve to improve communication with clients, while at the same time ensuring that no valuable information is lost.

5.1.3 Body functions

Unlike the activities and participation component and environmental factors, the chapter distribution in body functions was uneven, with a vast majority of categories representing mental functions. However, this is not surprising given that ADHD is operationalized as a brain-based condition with primarily neurocognitive impairments. Still, other areas of body functions were identified in this study, including cardiovascular and digestive functions, which has previously been reported in research with mixed results (Instanes et al. 2018; McKeown, Hisle-Gorman, Eide, Gorman & Nylund, 2013). The results underpin the importance of not only assessing mental functions in ADHD, but also somatic issues that may disrupt everyday life functioning.

5.1.4 Personal factors and ADHD-related strengths

Personal factors, which are regarded as inherent qualities of individuals that are not part of a condition or disorder, but may nevertheless influence functioning, were identified in the study. A majority of the concepts were perceived to facilitate everyday life functioning, with some touching upon personality traits and interests, while others exploring life habits and behavior patterns. The absence of an internationally, accepted classification system for personal factors makes it difficult to systemize information pertaining to this component. On the other hand, this study seems to support the importance of documenting personal factors, either descriptively or by using unofficial classification systems for personal factors (Grotkamp et al. 2012). Besides personal factors, this study also inquired about ADHD-related strengths and abilities, which generated diverse range of concepts. Some findings, such as creativity and hyper-focus, have been previously discussed in research (Healey & Rucklidge, 2005; Hupfeld et al. 2018). Having a high level of energy and drive was most commonly mentioned strength, which was also reported in the ADHD expert survey (i.e. the second preparatory study included in the development of ADHD ICF-CS), which involved 174 multi-professional, international experts in ADHD responding to questions about functioning and disability in ADHD (de Schipper et al. 2015b). At the moment, there are very few studies that have addressed individual strengths and resources in ADHD (de Schipper et al. 2015a). Pointing out certain skill sets and working with enhancing or reinforcing internal resources could potentially have beneficial effect in terms of treatment response or compliance (Gassman & Grawe, 2006). Nevertheless, few manuals or guidebooks exist that address individual strengths and resources in ADHD (Newark, Elsässer & Stieglitz, 2016). The ICF is unique in that it recognizes abilities and strengths in health-related functioning in addition to disabilities and weaknesses, providing stakeholders with opportunities to develop

tools from the ICF that allows documentation of strengths for assessment and intervention purposes.

5.2 STUDY II

As part of the preparatory phase to develop ICF-CS for ASD, study II aimed to investigate the experiences of diagnosed individuals, family members and professionals on relevant aspects of functioning and disability related to ASD. We also examined environmental and personal factors pertinent to ASD, as well as abilities and strengths associated with ASD. All four ICF components were represented, with most coming from activities and participation, followed by body functions and environmental factors. Only few body structures were covered. Personal factors deemed important to everyday life functioning were diverse. Recurring themes of ASD-related strengths were summarized.

5.2.1 Activities and participation

Similar to study I, the linking analysis yielded categories from all nine chapters in the activities and participation component, reinforcing the notion of ASD as a heterogeneous condition with diverse impact on individual functioning. Interestingly, several categories from the major life areas chapter were mentioned by the participants to be affected, including managing finances and transactions. Being able to manage own personal finances has previously been expressed by young individuals with ASD to be an important target for intervention (Cheak-Zamora, Teti, Peters & Maurer-Batjer, 2017), which is not surprising given that money management skills can lead to better overall independence, as well as improved psychological well-being and income attainment (Taylor, Jenkins & Sacker, 2011). Yet, little is known about the financial skills of individuals with ASD (Cheak-Zamora et al. 2017). One reason could be that these types of issues may be viewed as problems that should be addressed outside the purview of service providers working with young individuals with disabilities (Peters, Sherraden & Kuchinski, 2016). Another reason could be that financial autonomy is not prioritized as much as other issues in daily living, such as employment, social functioning and education (Lorenc et al. 2018). The advantage with the ICF is that it focuses on functioning and not diagnosis, meaning that it can address many areas in daily living that are deemed important by clients and family members, but don't receive enough attention in research or clinical practice. This study also found certain aspects of mobility to be affected in ASD, such as driving and using transportation, which are in accordance with previous research (Lindsay, 2017). The problems with mobility seem to be multi-faceted, caused by individual deficits (e.g. inability to sustain attention or handle unexpected events) and environmental barriers (e.g. absence of transportation options, expensive public transportation system) (Lindsay, 2017; Lubin & Feeley, 2016). By using the comprehensive framework of ICF, parents or clients can communicate their issues with mobility with ease and clarity, guiding the professionals to design interventions that are more in line with individual goals and needs. Such tools are highly desirable in clinical practice, especially given the discrepancy in what clients with ASD and their caregivers desire and what is being offered by service providers (van Schalkwyk & Volkmar, 2017). Recreation and leisure is

another area that invites to closer examination, as evidenced by the high frequency of stakeholder groups mentioning this particular area of functioning. Individuals with ASD tend to report less frequent engagement in recreational and community activities (Orsmond, Shattuck, Cooper, Sterzing & Anderson, 2013; Tobin, Drager & Richardson, 2014). Understanding social participation in ASD is vital, as it has a significant role in well-being, self-esteem and QoL (Carlberg & Granlund, 2019). Surprisingly, however, there is a limited focus on recreation and leisure in assessment of ASD (Castro et al. 2013). One explanation could be that many ASD-related assessment tools focus on establishing diagnosis by measuring overall functional status, rather than exploring functionality beyond the borders of diagnosis, which may be more tangible for intervention planning. Nevertheless, the ICF's inclusion of participation as important outcome measure can offer stakeholders meaningful means to assess frequency and intensity of activity engagement in individuals with ASD.

5.2.2 Environmental factors

Environmental factors were identified across all five ICF chapters (i.e. products and technology, natural environment, support and relationships, attitudes, services, systems and policies), which shows that all aspects of the environment are important to address in order to fully understand functioning in ASD. Interestingly, this study identified larger number and broader variety of environmental factors compared to the ASD literature review, which marked the first preparatory study in the development of ICF-CS for ASD (de Schipper et al. 2015c). Even though experts as well as clients and caregivers perceive environmental factors as an essential component in individual functioning, there is a limited availability of standardized tools assessing environmental factors in clinical practice (Castro et al. 2013). Traditionally, a medical model has been used in psychiatry to explain and treat NDD, including ASD (Deacon, 2013). The medical model seeks primarily to understand ASD from a biological perspective, emphasizing individual traits and weaknesses. Such approach could lead to interventions that are mainly designed to modify existing behaviors in ASD rather than removing environmental barriers to cope with everyday life demands. The importance of environmental facilitators has previously been demonstrated to assist individuals in navigating academic, occupational and social challenges (Anderson, Sosnowy, Kuo & Shattuck, 2018; Scott et al. 2018). The ICF differs from many of the other classification systems (e.g. ICD, DSM, ICIDH) in that it permits stakeholders to identify concrete barriers and facilitators in the environment. The information that is generated can provide stakeholders a clear overview of areas that could be targeted to promote inclusion among individuals with ASD. Examples could include using electronic devices to facilitate communication and social interaction (Scott et al. 2018), or providing transportation services that would allow individuals to live more independently (Anderson & Butt, 2018).

5.2.3 Body functions

Body functions were identified across different chapters, although most pertained to mental and sensory functions, both part of the core behavioral domains of ASD. There were some digestive functions that were also covered, in line with our preparatory studies, which

involved a literature review (de Schipper et al. 2015b) and an international expert survey (de Schipper et al. 2016). However, this study identified larger number of digestive functions, suggesting that these functions may be of particular importance to clients, family members and caregivers. Gastrointestinal issues (GI-issues) can have an impairing effect on social relationships, domestic life, financial situation and work (Bennett et al. 1998), which is why it is important that these issues get addressed. For this to be possible, a transdiagnostic approach is needed, where healthcare professionals from different disciplines can work together to identify problems and formulate treatment plans that involve accounting for somatic complaints in individuals with ASD. The utility of the ICF is that it emphasizes functional health, meaning that it is not confined to professional or diagnostic boundaries. As such, the ICF framework can be implemented by healthcare professionals who adhere to using a transdiagnostic service approach.

5.2.4 Personal factors and ASD-related strengths

Similar to study I, plethora of personal factors were identified here, ranging from certain personality factors (e.g. empathetic, sense of right and wrong) and life habits (e.g. playing with devices, listening to music) to personal attitudes (e.g. acceptance of own diagnosis) and behavior patterns (e.g. accepting challenges, trying new things). Interestingly, the latter may be seen as contradictory to the diagnostic criterion restricted behavior patterns and interests. On the other hand, it is a well-known fact that there is an extreme variation in how symptoms are expressed in the ASD population (Constantino & Charman, 2016), which further supports the idea of having a functioning-oriented perspective towards individual assessment of ASD. Assessing personal factors can also be valuable in terms of using these to design interventions that are more motivating and closer to individual desire (Geyh et al. 2011). In addition to personal factors, ASD-related strengths were mentioned by the participants in the different stakeholder groups, among which included cognitive functions such as memory and attention. Certain personality and temperament functions were also acknowledged, including honesty and loyalty. While the results corroborate previous findings (Schall, Wehman & McDonough, 2012), there is still minimal research on how to implement these in daily practice to support individuals with ASD in their pursuit of interests and abilities (Jones et al. 2018). Given that the ICF also acknowledges abilities and strengths, users can apply the ICF framework to create support programs that aim to utilize individual strengths in ASD. In Australia, strength-based programs have been introduced to create safe environment for adolescents with ASD to engage in activities they excel at (e.g. computer programming, playing games) (Jones et al. 2018). Such programs can create opportunities for autistic individuals to establish contact with peers, share own interests, learn new skills and become more integrated in society.

5.3 STUDY III

Study III was included in the development project of ICF-CS for ADHD, aiming to investigate the clinical perspective on functioning and disability, as well as environmental and personal factors in ADHD using an international cross-sectional study design. Study III

also examined ADHD-related strengths and abilities. Categories were identified from all ICF components, except for body structures. A wide variety of personal factors and ADHD-related strengths were covered in the study as well.

5.3.1 Activities and participation

The activities and participation component had the largest coverage of ICF categories, with all nine chapters represented. Not only does this affirm the heterogeneity of ADHD, but it also shows that ADHD is a life-long condition that continues to persist into adulthood, causing significant disruptions in adult life, including occupation (e.g. remunerative employment), financial status (e.g. economic self-sufficiency), domestic life (e.g. preparing meals) and transportation (e.g. driving). The results here are consistent with previous research, which shows that although ADHD symptoms may decrease with age, the impact on functioning is still significant (Simon et al. 2009). This study also found several aspects of communication (e.g. understanding verbal and nonverbal communication, producing nonverbal messages, conversational skills) to be affected in ADHD, deviating significantly from the three previous preparatory studies (i.e. scoping review, expert survey, qualitative study) which yielded one category altogether. The results may in part reflect the presence of comorbidities (i.e. ASD, communication disorders) in some cases that were assessed, although the clinical researchers were carefully instructed to focus on ADHD. Nevertheless, some individuals with ADHD do exhibit communication difficulties (e.g. reacting to cues, conversation skills) that are caused by ADHD symptoms (e.g. lack of impulse control, inattentiveness) (McQuade & Hoza, 2008), warranting a closer examination of these in daily practice.

5.3.2 Environmental factors

Environmental factors were identified across all five chapters, signifying the importance of inquiring about different aspects of the environment when assessing functional health in ADHD. Several categories were identified from the attitudes chapter, which touched upon the opinions, values and beliefs about ADHD. The results here are in line with previous research, which show that public's opinions about ADHD can have a significant effect on daily life functioning, including academia, social relationships and treatment adherence (Lebowitz, 2016; Mueller, Fuermaier, Koerts & Tucha, 2012). Historically, ADHD has been subjected to great scrutiny concerning its validity as a bonafide condition (Lebowitz, 2016). An unwillingness to accept ADHD as a true condition could lead to individuals attributing symptoms to being lazy or disobedient, hence limiting opportunities for individuals to receive appropriate care and support. Lack of intervention may in turn exacerbate symptoms and reduce functioning status. While public perceptions or attitudes can be difficult to target through intervention, it is important that professionals who work with clients with ADHD also involve their caregivers and teachers to inform them about the impact that environmental barriers can have on individual functioning. The ICF framework allows professionals to emphasize social influences on health-related functioning, providing them with concrete means to communicate the role of the environment to parents, friends and teachers. Another

chapter that was widely covered was services, systems and policies, which can be explained by the fact that ADHD has a significant impact on everyday life functioning, hence requiring the assistance of various agencies. Still, in some societies, services remain limited for individuals with ADHD. For example, in Sweden, the Swedish Act concerning Support and Service for Persons with Certain Functional Impairment (1993) does not usually include individuals with ADHD, but rather other conditions that are deemed more disabling, such as ASD and intellectual disability. A diagnosis is only intended to provide a general overview of challenges and support needs, and does not account for other vital dimensions, such as participation, inclusion and QoL. In other words, diagnosis does not yield sufficient information on daily life functioning, meaning that it would be futile to use diagnosis as basis for resource allocation, especially in the NDD population given its considerable variation in functional status. The assessment tools derived from the ICF-CS for ADHD can address this issue, as it focuses on generating unique functioning profiles that will allow professionals to acquire better overview of individual challenges and needs for resource allocation purposes.

5.3.3 Body functions

Body functions consisted primarily of mental functions, but other areas of the body were also identified, including sensory, musculoskeletal, gastrointestinal, reproductive, speech and respiratory functions. The findings here replicate previous research which show the impact of ADHD to stretch out and include other body processes than mental functions (Fliers et al. 2008; Instanes et al. 2018; Niemczyk et al. 2015; Stickley, Koyanagi, Takahashi & Kamio, 2016). Dysfunction in the brain's dopamine system has been suggested to underlie some of the physical impairments that can be observed in the ADHD population (Fliers et al. 2008; Kooij, 2016; Stickley et al. 2016). Regardless of pathophysiology, it is evident that the assessment of ADHD needs to include an interdisciplinary service approach where diverse range of professional expertise can be utilized to address both psychiatric and physical complaints. However, a unified framework to communicate findings across professional boundaries is lacking (Terner et al. 2012). Given that the ICF provides a standardized coding scheme which enables information to be collected across different users and stakeholders, tools derived from the ICF-CS for ADHD can serve as a first step towards promotion of interdisciplinary collaboration and communication. In this study, no body structures reached the 10 % cut-off, which can be explained by the fact that anatomical examinations involving neuroimaging are currently not an integral part of the international standard of diagnosing ADHD.

5.3.4 Personal factors and ADHD-related strengths

In addition to assessing functioning and environmental factors, this study also documented personal factors that were perceived to either facilitate or hamper individual functioning. This study found certain facilitatory factors, including empowerment, to help individuals navigate through hardships in life, enabling them to succeed in academia or work. Interestingly, this finding is consistent with a qualitative study that was conducted by Ek and Isaksson (2013) which showed individuals with ADHD to gain pleasure from applying effort to reach a

certain goal in life. Another factor that was mentioned to aid participants in life was having a positive attitude towards the ADHD diagnosis. Although the public's attitudes towards individuals with ADHD has been highlighted in research, there are limited number of studies examining individuals' own attitudes toward the diagnosis. Nevertheless, it is important that professionals can document facilitatory factors in daily practice, as these can have a significant impact on how individuals choose to engage in treatment or other tasks in daily living (Morsink et al. 2017). Hampering personal factors involved past traumatic life events (i.e. getting bullied) and engaging in current life habits, such as physical inactivity or drinking alcohol. To our knowledge, this is the first international clinical study that involved using the ICF framework to rate strengths in individuals with ADHD. The strengths varied quite considerably, and some even contradicted the clinical presentation of ADHD. For example, memory and attention were identified as strengths, which deviates from the symptomatology involving forgetfulness and inattentiveness which are usually observed in the ADHD population. One theory could be that the cognitive profiles of those with ADHD could oscillate from one extreme (inattentiveness/forgetfulness) to another (hyper-focus/strong memory skills) depending on how interesting an activity is perceived. Deficits in motivation has previously been identified as a factor that may contribute to dysregulation of attention and other cognitive functions in ADHD (Volkow et al. 2011). Different categories pertaining to interpersonal interactions and relationships were also rated as strengths. Although social difficulties are common among individuals with ADHD, some remarked that years of practice and learning social skills helped them to form deep social bonds, whereas others mentioned an inherent ability to approach people and initiate meaningful interactions. Given that the ICF views functional health in a dimensional manner, tools from the ADHD Core Sets can facilitate assessments and interventions that serve to balance out deficit-oriented views of ADHD, increasing public awareness about ADHD as a condition that is far more complex than its core behavioral domains.

5.4 STUDY IV

Using an international cross-sectional design, study IV sought to explore the clinical perspective on functioning and disability in ASD, as well as environmental and personal factors, as part of the international development of ICF-CS for ASD. Study IV also examined ASD-related strengths and abilities. Categories were identified from all ICF components, except for body structures. A wide variety of personal factors were identified. Only few ASD-related strengths reached the 10 % cut-off.

5.4.1 Activities and participation

All nine chapters in the activities and participation component were covered in the study, in line with previous research on difficulties with communication, social interaction, learning, self-care, domestic life and conductance of general tasks and demands (Borremans, Rintala & McCubbin, 2010; Fortuna et al. 2015; Matson, Dempsey & Fodstad, 2009; Schmidt et al. 2015). There were, however, aspects of daily life activities and participation that were identified in the current study as affected, but not extensively examined in research. These

particularly include categories in the community, social and civic life chapter, i.e. community life, religion and spirituality, and political life and citizenship. Some of the limitations and restrictions were mentioned to be caused by negative stereotypes about the capacity of autistic individuals to engage in self-advocacy, reporting that they felt excluded in issues that pertained to them (e.g. how to organize services in society for individuals with ASD, what to address in intervention planning, etc.). Participation in community activities, including political and religious spheres, has previously been highlighted in the UNICEF CRPD. Participation in these types of activities can facilitate integration in society, enabling individuals to establish social contacts, engaging in civil duties and responsibilities, and experience feelings of togetherness and comfort. Consistent with previous research, participation in social and community activities have been found to be an important predictor of QoL in individuals with ASD (Lin & Huang, 2019; Schmidt et al. 2015). Yet, these aspects of daily living are rarely addressed in assessment, making it difficult to target these with interventions (Castro et al. 2013). The ICF-CS for ASD can offer clients and family members a chance to communicate needs related to community and civic life with proper assessment tools that document functional information beyond the boundaries defined by diagnostic criteria, extending into issues that deal with participation in community, social and civic life. Another interesting finding was usage of public motorized transportation, which was also addressed in study II. However, in this study, we identified additional challenges related to using transportation, which included coping with stressful events (e.g. crowded spaces, rush hours). The benefit with using the ICF coding scheme is that it can demonstrate for professionals and clients how different aspects of functioning and environment may influence each other in a pedagogical manner. For example, sensory issues (impairments in body functions) may cause individuals to avoid crowded places, including metro stations (limitations in using transportation). At the same time, there are no transportation services available that would allow individuals to use alternative means of transportation (e.g. environmental barrier). The absence of such option could consequently restrict individuals from visiting friends, attending work or engaging in recreational activities (restrictions in participation). By structuring information into different components, it can help clients, family members and professionals to better understand how daily life functioning is impacted as a whole, as well as provide insights into what to target for intervention purposes. This could also facilitate closer collaboration between professionals, clients and family members, which is highly desirable in daily practice (Swedish Council on Health Technology Assessment, 2013b).

5.4.2 Environmental factors

Similar to study II, all five chapters in the environmental factors component were rated to be important to individuals with ASD. The natural environment of individuals with ASD was one of five chapters that was addressed, which included sound, light and climate. A closer examination found that a majority of these categories were rated as barriers, which is not surprising, given the fact that sensory issues, irrespective of age group, are quite prevalent in the ASD population (Ben-Sasson et al. 2009; Tavassoli, Miller, Schoen, Nielsen & Baron-

Cohen, 2014), hence making them more vulnerable to noises, extreme temperature or light intensity. This study also covered several categories from the support and relationships chapter, corroborating previous research results which show that the support from peers, colleagues, employers and professionals can facilitate successful outcome in daily living, including employment, academia and social relationships (Askari et al. 2015; Dreaver et al. 2019; Kirby et al. 2016). The services, systems and policies chapter consisted of categories that covered breadth areas of services providers, ranging from housing, transportation and general social support to social security, healthcare, education and labor and employment services. The findings here suggest that different types of services are important to individuals with ASD in order to optimize outcome in everyday life functioning, which is consistent with previous research (van Schalkwyk & Volkmar, 2017). Nevertheless, some clients and caregivers cited lack of service cohesion and interagency communication as main obstacles to accessing care. In fact, some remarked that they were nearly giving up on applying for support services due to the strenuous and time-consuming process of getting in touch with different agencies, providing them with necessary documentation and explaining their needs multiple times. The lack of service cohesion and interagency collaboration may partly be attributed to agencies having their own eligibility criteria or framework for providing care and support, which may vary across different organizational systems, resulting in lack of consensus on how to organize care and support (Whittle, Fisher, Reppermund, Lenroot & Trollor, 2018). Another factor that can complicate the process of receiving appropriate care is the lack of clarity around the scope and remit of different service providers. For example, if assessments are done in psychiatry, but referrals are made to habilitation services for intervention purposes, then there must be a common standard or framework in place that would allow findings from assessments to translate into clear targets for intervention planning. A lack of such framework could lead to confusion or uncertainty regarding intervention planning, hence requiring new assessments involving clients and caregivers taking part all over again. The strength of the ICF is that the taxonomy consists of standardized terminologies and descriptions about health-related functioning and disability, meaning that future users of ICF-CS for ASD will be able to communicate results from assessments to other service providers with better clarity and ease.

5.4.3 Body functions

Although the majority of body function categories came from mental functions chapter, other areas of the body were found to be altered, which is consistent with previous studies about sensory issues (Ben-Sasson et al. 2009; Tavassoli et al. 2014), speech disfluency (Scaler Scott, Tetnowski, Flaitz & Yaruss, 2014), gastrointestinal problems (McElhanon et al. 2014), musculoskeletal impairments (Dufek et al. 2017; Travers et al. 2013) and immunological deficits (Lyall et al. 2015). Unlike study II and other ICF-CS preparatory studies (de Schipper et al. 2015c; de Schipper et al. 2016), this study identified additional body functions to be impaired, including sexual functions (e.g. sexual interest, masturbation). Research on ASD and sexual functions is limited, which is surprising given the extensive coverage of difficulties in social interactions among individuals with ASD and the fact that sexual

functions play a significant role in creating and maintaining intimate relationships. One reason could be that there are false beliefs and stereotypes about individuals with ASD being uninterested in romantic relationships and intimacy (Schöttle, Briken, Tüscher & Turner, 2017), which may cause researchers or clinicians to overlook impairments in sexual functions. Another reason could be that sexual issues may be deemed too stigmatizing to discuss in clinical practice, or that communication difficulties could restrict individuals from explaining needs for proper sexual education. Nevertheless, this study highlights the need for closer examination of sexual functions in ASD.

5.4.4 Personal factors and ASD-related strengths

Personal factors included both supportive and hindering factors that were mentioned to impact individual functioning. The former consisted of factors such as acceptance towards own diagnosis, having high IQ and enjoying special interests, whereas the latter was composed of having caregivers with psychiatric disorders, going through traumatic life experiences and being perfectionist. The importance of emphasizing special interests in children, youth and adults with ASD by allowing them to engage in their activities and cultivating their talents have previously been demonstrated in research (Jones et al. 2018). Not only can participation in special interests serve to increase individual well-being, but also provide opportunities for individuals to meet other peers who share similar interests, and thus offer them opportunities to practice their social interaction skills in safer environments. However, to identify these facilitatory factors, it is important that professionals not only inquire about functional impairments or limitations, but also what type of activities individuals enjoy doing, as well as how the environment can assist them in accommodating their interests. For this to be possible, a framework is required that is holistic, taking into account individual factors. Although the ICF does not classify personal factors into codes, it can nevertheless raise awareness about inquiring about these issues in practice. Traumatic life experiences (e.g. bullying) were mentioned to negatively influence self-esteem and self-worth of individuals, while perfectionism was cited to hinder individuals from engaging in activities or taking on new tasks and assignments in life. While there are advantages with inquiring about supportive personal factors, it is important that hampering factors are treated with caution, as these may be misused in a way that includes “blaming the person” for their functioning limitations rather than strengthening the individual’s perspective when discussing plans for interventions or assessments. Therefore, it is important that there is a clear purpose with documenting personal factors, and that clients or caregivers feel secure about sharing information about hampering factors. Regarding ASD-related strengths, few were identified, which included memory and attention, which were also found in study II.

5.5 LIMITATIONS AND CONSIDERATIONS

Although all studies involved an international sample of participants, certain WHO-regions were underrepresented or not even covered. This limits the global generalizability of the findings. It is important to stress that the development of ICF-CS for ADHD and ASD will not only be based on results from the qualitative and clinical studies, but all studies, including

the expert survey and systematic literature review, which had larger representation of countries or WHO-regions that perhaps were not as extensively covered here. In study I and II, transcriptions were translated into English, which meant that certain cultural expressions and their exact connotations were either lost or modified in the process. This made the linking a bit more challenging, as evidenced by the fair level of interrater agreement across study sites. While linking of transcriptions were done in collaboration with a researcher located at KIND for the purpose of standardization, future studies should perhaps look into using independent researchers doing the linking directly in their native language. Interestingly, there were some ICF categories and chapters which the independent researchers had different opinions about based on their professional background. For example, problems with sensory processing (e.g. noise, light) was perceived to be b156 Perceptual functions by the psychologist involved in the linking, while the other researcher, an occupational therapist, deemed the concept to be part of b2 Sensory functions and pain chapter. This shows that although the ICF provides a unifying framework to communicate findings across professional boundaries, there may still be some differences of opinions with regards to how functioning and disability are classified and operationalized in the ICF. Another limitation pertains to the limited number of certain stakeholders who participated in the qualitative studies, specifically children and adolescents, as well as intellectual disabled autistic individuals in study II, and school personnel in study I. Considering that the development of ICF-CS project emphasizes the perspective of clients and caregivers, larger number of younger participants with ASD should have taken part in the study. There were, however, some challenges with recruiting younger participants with ASD, as some parents had reservations about whether their children would be able to provide meaningful answers given their issues with communication and insight. While certain adaptations were made to facilitate communication (e.g. allowing parents to present, communicating questions non-verbally, providing papers to draw sketches), future studies should perhaps look into applying cue cards that would enable more efficient communication with younger participants with ASD. On the other hand, any modifications may be futile if participants lack insight into own strengths and difficulties, which is why we were mindful about reminding family members who had young children with ASD to also provide answers that would reflect their children's views on functional health. In study III and IV, most adults were assessed without access to medical records, meaning that information mainly relied on interviews with participants. In future studies, it is desirable to involve clinical units who specialize in assessing adults with ADHD and ASD. However, this can be challenging, as services for adults with ADHD and ASD are in general limited (Ginsberg et al. 2014; Shattuck et al. 2012), particularly in low to middle income countries (de Vries, 2016). With regards to gender and age differences, no analyses were done in study III and IV, mostly due to uneven representation of groups (e.g. age group, gender), but also because of many confounding factors (e.g. culture, comorbidity, symptom presentation, information sources, etc.). Furthermore, in study IV, the limited number of clinical cases involving comorbid intellectual disability in ASD raises the question about biased representation of categories. However, as the study identified large and broad number of candidate categories, we expect the results to have covered the functional outcome of those

with comorbid intellectual disability. Finally, no inter-rater reliability assessments were conducted in study III and IV, mainly due to the cross-cultural character of the studies with many different languages involved. To address this, the investigators were strictly encouraged to collaborate with one another and seek consensus on ratings. When rating the clinical cases, the investigators mentioned that certain environmental factors categories were a bit difficult to rate, as some (e.g. e410 Individual attitudes of immediate family members) were deemed both a barrier (e.g. a father who does not think that ASD exists) and a facilitator (e.g. a mother who is open to learn more about ASD to understand her son better) at the same time. This supports the need for a modified coding scheme that would allow users to differentiate and specify certain environmental chapters even further in the ICF (Zakirova-Engstrand & Granlund, 2009).

6 CONCLUSIONS AND FUTURE DIRECTIONS

This thesis included a series of studies that aimed to explore functioning and disability in ADHD and ASD as part of the preparatory phase to develop ICF-CS for ADHD and ASD. Study I and II included clients with ADHD and ASD, family members and professionals, whereas study III and IV consisted of clinicians who rated the functioning level of clients with ADHD and ASD.

Notwithstanding the limitations, the following conclusions can be made based on this thesis: (1) There is a broad variation of activity limitations and participation restrictions among individuals with ADHD and ASD, meaning that diagnostic information is insufficient to capture the everyday life experiences of individuals with ADHD and ASD. (2) All types of environmental factors are important to evaluate when assessing health-related functioning in ADHD and ASD, as these can either reduce or enhance individual functioning. (3) Impairments in body functions do not only consist of mental functions, but also other areas that are not part of the core behavioral domains of ADHD and ASD, such as digestive, musculoskeletal and genitourinary functions, hence highlighting the need for interdisciplinary assessment and intervention approach. (4) Personal factors, although not classified in the ICF, can generate additional information about the lived experiences of individuals with ADHD and ASD which may be important to emphasize for intervention or assessment purposes. (5) ADHD and ASD is not only associated with weaknesses or deficits, but also strengths and skill sets, which can be useful to address in assessment settings in order to design interventions that are founded in reinforcing individual resources.

The findings of the qualitative and clinical studies were presented along with results from the other preparatory studies (i.e. literature review, expert survey) in a consensus conference, which entailed international experts from different professional backgrounds reviewing the study findings, and based on an iterative decision-making process, developing first versions of Comprehensive and Brief ICF-CS for ADHD and ASD, as well as age-specific sets that cover different age groups of individuals with ADHD and ASD (0-5 years; 6-16 years; $\geq$ 17

years of age) (Bölte et al. 2018; Bölte et al. 2019). The Comprehensive ICF-CS includes larger number of ICF categories, capturing the entire spectrum of problems that individuals with a certain health condition may encounter in real life (Bickenbach, Cieza, Rauch & Stucki, 2012). Given the extensive number of categories included in this set, the Comprehensive ICF-CS can be applied in larger, multidisciplinary settings that involve comprehensive assessments of functioning for intervention purposes. The Brief ICF-CS contains fewer number of categories and is intended to be used as starting point for basic documentation of functioning, which may be suited in places where a brief assessment of functioning is necessary (e.g. research, single-discipline settings). The development of ICF-CS is usually followed by a validation and implementation phase, which consists of deriving user-friendly tools from the ICF-CS and implementing these in daily practice (Selb et al. 2015b). While plethora of ICF-CS have been developed for different conditions [www.icf-core-sets.org], only few have proceeded to validating and implementing these in daily practice (Schiariti et al. 2018). The implementation phase poses a major challenge, as there is no clear gold standard procedure for how to implement the ICF-CS in daily practice, differing from the preparatory phase which followed a standardized, rigorous, scientific procedure as defined and monitored by the WHO and ICF Research Branch (Selb et al. 2015b). One reason for the lack of gold standard procedure could be that ICF-CS are aimed to be used in different settings and countries, meaning that tools that are derived from the ICF-CS need to be adapted and modified to serve specific purposes. Indeed, some settings or countries may for instance be interested in deriving tools from the ICF-CS to conduct comprehensive functioning assessments with operationalized items (Schiariti et al. 2018), whereas others may be more interested in using the categories in the ICF-CS to evaluate content validity (Jobst, Kirchberger, Cieza, Stucki & Stucki, 2013). For this reason, it is vital that the purpose and context of the specific study site or service provider that is interested in applying the ICF-CS is clearly outlined, otherwise it will be difficult to know how or what type of tools to derive from the ICF-CS. At KIND, we intend to derive computer-based questionnaires [e-tools] from the ICF-CS to standardize individual assessment of functioning and disability in ADHD and ASD across different settings that may represent important arenas for individuals with ADHD/ASD (e.g. habilitation, psychiatry, schools/special schools, employment agency, etc.). Given that the questionnaires will be rated by clients (adults, older adolescents), parents (proxy-reports) and professionals (e.g. clinicians, educators, researchers, etc.), the codes in the ICF-CS need to be operationalized into hands-on items that are easy to understand and rate. A first draft of operationalized items will be made and sent to an international expert panel for review. The expert panel will consist of interdisciplinary ADHD and ASD experts as well as experienced ICF researchers who will provide feedback on the items and discuss the implementation phase in more detail. The questionnaire will also include instructions on how to rate each specific ICF code and what type of information to use while doing the scoring (this part only pertains to expert ratings). Herein lies the challenge of translating clinical information (e.g. results from standardized instruments) into ICF qualifiers, as many standardized instruments have not yet been linked to ICF categories (Schiariti et al. 2018). Given that standardized instruments play a major role in assessments of ADHD and ASD, the

content of these need to be linked to ICF categories in order to save time and enable more efficient transmission of information. To address this, there is an ongoing project aiming to link subscales of instruments into ICF categories, covering different areas, such as behavior problems, abilities, adaptive functioning, cognition, sensory functions and core symptoms. The idea is to provide a linking glossary for professionals who aim to score ICF items based on results from standardized instruments. To individualize functioning assessments, users can choose to add ICF codes, write personal factors, or document other relevant contextual information that is considered pivotal to complete the assessment of functioning. Once a first draft of the prototype has been finalized, it will be reviewed by stakeholders (e.g. professionals, experts, clients, family members) to check for concept clarity as well as feasibility of using the assessment tool. Provided comments are used to make final modifications to the prototype. The next phase will consist of piloting the prototype in Sweden and across different international study sites to collect information on feasibility using both quantitative and qualitative outcome measures. Subsequently, the ICF-CS prototype will be revised based on the qualitative feedback and feasibility ratings. These e-tools will then be psychometrically evaluated with both reliability (e.g. intra, interrater reliability, test-retest) and validity assessments (e.g. convergent, concurrent validity).

The ICF-CS can be used to facilitate multidisciplinary assessment and collaboration (Bickenbach et al. 2012), which is highly desirable for professionals working with ADHD and ASD, as these conditions tend to impact many areas of functioning that require interdisciplinary expertise and care management. Given that the ICF-CS for ADHD and ASD represent multiple components (e.g. environmental factors, body functions, activities and participation) and diverse range of functioning domains (e.g. mental functions, motor functions, self-care, domestic life, etc.) (Bölte et al. 2018; Bölte et al. 2019), it is evident that the assessment of functioning in ADHD and ASD needs to be distributed among different members of an interdisciplinary team in order to implement the ICF-CS successfully in clinical and daily practice. A protocol should be in place that shows the responsibility of the different professional disciplines in conducting functioning assessments (Bickenbach et al. 2012). For example, psychologists may primarily be involved in assessing mental functions and communication in ASD, whereas occupational therapists may be more involved in assessing activities of daily living (e.g. self-care, domestic life) and participation-related issues (e.g. employment, recreation). While some ICF categories (e.g. mobility) may require assessments from more than one professional discipline (physiotherapists, occupational therapists), it is important for clarity purposes to know which professional discipline is in charge of making the final rating of ICF-category. Hence, the implementation of ICF-CS requires close collaboration and communication between the different professional disciplines. A full depiction of an individual's functioning profile can be made once the professionals apply the ICF qualifiers to rate the magnitude of functioning impact using information from various sources (e.g. medical history, clinical examination, test-results, questionnaires, etc.). Such functioning profile can serve to improve communication with family members and clients by allowing information to be structured in a systematic way,

with clear information on individual limitations and strengths, as well as important contextual factors (personal factors, environmental facilitators and barriers) (WHO, 2001; 2007). By involving parents and clients in the assessment procedure, the professionals can discuss the results found in the assessment, and in agreement with the client and/or family member, design plans for intervention and goal-setting. The unique functioning profile acquired from the assessment makes it possible for professionals, clients and family members to highlight areas of priority in accordance with individual goals and demands. The functioning profile can also serve to facilitate access to appropriate care and resources from different service providers (e.g. social, education, employment) by coding information from assessment in a detailed and structured manner, enabling service providers to get a quick overview of individual limitations and demands. Another advantage with the ICF-CS is that environmental factors can be properly assessed, thus enabling professionals and clients to highlight environmental barriers and facilitators to emphasize the responsibility of the environment in making proper adjustments rather than relying exclusively on modifying individual traits to fit environmental demands. The former is more in line with the CRPD, which stresses the importance of the environment in ensuring that individuals with disabilities are offered equal access to participation in society. The assessment of environment can also make it easier for professionals to evaluate the effects of services and interventions on health outcome and as such offer clients and family members a chance to voice their opinions on services they have received from society. Besides environmental factors, the ICF-CS can be used to assess individual strengths, skills and resources, as the ICF views functional health in a dimensional manner. Such assessments can be viewed less stigmatizing and provide important information that can serve to encourage clients to pursuit interests and reinforce already existing strengths and skill sets that may be beneficial in daily life.

Interestingly, the ICF-CS can also be used in non-clinical settings (Bickenbach et al. 2012). For example, the Swedish Social Insurance Agency will be using the ICF-CS for ADHD and ASD as basis for evaluating individuals' ability to work and conduct different activities of daily living for resource allocation purposes. The ICF-CS for ADHD and ASD comprises categories across all domains of activities and participation (Bölte et al. 2018; Bölte et al. 2019), enabling users to assess functioning and disability in different contexts (e.g. self-care, domestic life, mobility). The ICF-CS can also be used in employment agencies, specifically in units working with neurodevelopmental assessments to tailor special support at workplaces for individuals with disabilities. The ICF-CS can act as a tool to enhance communication between service providers, employees and employers, while at the same time enable comprehensive assessments to be made at workplaces to inform on possible environmental modifications.

Although there are several advantages with using the ICF-CS in clinical and daily practice, there are some challenges and needs that need to be acknowledged. While ICF-CS have been developed for different conditions and health contexts, not many have proceeded to derive assessment tools from the ICF-CS (Schiariti et al. 2018). To justify the usage of such assessment tools in practice and research, these need to be psychometrically evaluated. For

example, it is unclear how well ICF-CS based assessment tools correlate with other well-established scales for ADHD and ASD, which makes the validity of the ICF-CS questionable. The level of item consistency in the ICF-CS for ADHD and ASD is another issue that needs to be properly addressed, as well as consistency of ratings over time (test-retest reliability). Moreover, norms need to be generated for the items in the ICF-CS in order to evaluate individual results in practice. Even though the ICF may suggest "0" to be expected for typically developing individuals, this might not necessarily reflect reality, which is why normalization is meaningful, as it provides a reference point which enables results to be compared to the general population matched by age, sex and location. Future studies should also investigate how the different components and categories in the ICF-CS relate to each other. While the ICF framework states that there are bi-directional influences taking place between the different components (WHO, 2001; 2007), there are no descriptions in the coding scheme for how the different components or categories may influence each other in real life (Magasi et al. 2015). This could make it difficult for users to integrate results from the assessment and explain how the different categories and components are related to each other. It's important to remember that the ICF-CS for ADHD and ASD should be viewed as dynamic rather than static, meaning that they will be subjected to changes over time as more studies are conducted. The ICF-CS for ADHD and ASD provides a starting point for future studies that will serve to validate and standardize individual assessment of functioning in ADHD and ASD across different settings, regions and countries. The intention is in the long run to implement ICF-CS based assessment tools in practice to endorse a functioning-oriented perspective on ADHD and ASD, shifting focus from psychopathology and impairments towards viewing health in a more nuanced manner to improve assessment, intervention planning and resource allocation.

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